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FACTORS ASSOCIATED WITH ADHERENCE TO ANTIRETROVIRAL THERAPY FOR THE TREATMENT OF HIV INFECTED WOMEN ATTENDING AN URBAN PRIVATE HEALTH CARE FACILITY

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DEDICATION

I dedicate this work to my husband and parents. Your inspiration, love and support made this all possible.

Op die ou end is die somtotaal
Die lesing op jou lewensskaal
Nie rykdom en aansien
Prag of praal –
Maar dit wat jy gee
En weer verhaal - *Mamma*

Dankie Mamma, Pappa en Mamma Rina



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Each participant for imparting her expert experience and knowledge on adherence to antiretroviral therapy.



ABSTRACT

Factors that impact on adherence to antiretroviral therapy are often entwined and poorly understood. South Africa is severely affected by HIV/AIDS and on the brink of a national antiretroviral roll-out. It became important to determine these factors.

A qualitative research design was used to further explore this subject and act as a basis for further research.

Significant correlation was found with international data. Most participants in this study indicated that traditional beliefs did not interfere with their adherence, but in the presence of inadequate knowledge regarding HIV, patients may revert thereto. Culture puts women in a submissive role and consequently reduces their negotiating power.

Treatment preparation and HIV education, combined with the patient-provider relationship, were considered important.

Identifying these factors and managing it through open communication channels and reliable access to information, remains a challenge.

KEY WORDS: Adherence, women, antiretroviral, factors, culture, religion, support, provider, emotions, knowledge, financial, belief

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CHAPTER 1

INTRODUCTION AND ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Adherence to treatment is an indication of the degree to which a patient follows advice regarding the treatment (Hsu, 2005). Adherence is a renowned predicament in the successful management of the Human Immunodeficiency Virus (HIV) in the speciality field of antiretroviral therapy. Adherence is not as simple as taking or not taking medication, but it is also taking the correct dose at the correct times together with the proper dietary requirements. Patients sometimes misunderstand dosing instructions and would unknowingly adhere well to a flawed regimen (Hill, Kendall & Fernandez, 2003:521). As it is demanding to adapt to the requirements of a long-term treatment plan, great care should be taken to ensure that patients understand their prescriptions. This intervention can prevent unnecessary risk of developing virus resistance, especially in patients who are motivated to make a success of their antiretroviral therapy, as doctors and other healthcare personnel often fail to recognise inadequate adherence.

Different factors influencing adherence, combined with an inability to measure it accurately, leave the health care team with a great challenge in the battle against HIV (Bangsberg, Hecht, Clague, Charlebois, Ciccarone, Chesney & Moss, 2001:437-439; Miller & Hays, 2000:[2]¹).

'In the face of remarkable medical advances, it is especially distressing that evaluation of patient adherence ... remains an imperfect science at best' (Turner & Hecht, 2001:[1]).

¹ The document pages were not numbered. To indicate to the reader where the information can be found, the pages were counted from the front and the resulting number indicated by square brackets

Of the estimated 39.4 million people living with HIV in the world, approximately 25.4 million of those are living in sub-Saharan Africa. This amounts to approximately 64.46% of the global HIV positive population (UNAIDS/WHO, 2004:3). South Africa as part of sub-Saharan Africa is severely affected by the HIV epidemic. This implies that many patients would potentially start on antiretroviral therapy in the near future. If antiretroviral therapy were to be successful in South Africa, healthcare providers will need to deal assertively with this problem.

Virus resistance towards antiretroviral drugs develops in cases of inadequate adherence. Selective pressure exerted by the inadequate use of antiretroviral drugs causes rapid emergence of mutations, drug resistance and subsequent increase in the viral load. This is especially applicable with drugs that can be administered once daily. In this instance, missing a single dose can cause the drug level to fall below the minimum concentration level required for sustained virus suppression (DHHS, 2004:2, 21; Lucas, 2004).

Once daily dosing is an important focus in antiretroviral therapy research. Research has proved that reduced pill burden and less frequent doses will ultimately improve adherence. This also allows for Directly Observed Therapy (DOT) under specific circumstances, as well as tailoring antiretroviral therapy according to a patient's lifestyle (Lucas, 2004). The United States Food and Drug Administration (FDA) already approved several antiretroviral drugs for once daily dosing while others are still being researched (Online, 2005). Although most of these drugs are not currently available in South Africa, many patients are using at least one drug that is administered only once a day.

The drugs approved by the FDA for using once daily are summarised in Table 1.1. Drugs that are currently under investigation for potential use in once daily administration are summarised in Table 1.2.

Table 1.1 Antiretroviral drugs approved by the FDA for once daily dosing

Abacavir (Ziagen) 600mg
Abacavir/Lamuvudine 600/300mg *
d4T (Zerit) XR 100 or 75mg (not commercially available) *
ddl (Videx) EC 400 or 250mg *
Emtricitabine 200mg *
Lamuvudine (3TC) 300mg
TDF (Viread) 300mg *
TDF/FTC (Truvada) 300/200mg *
Efavirenz (Stocrin) 600mg
Atazanavir 300mg * + Ritonavir (Norvir) 100mg
Atazanavir 400mg *
Fosamprenavir 1400mg * + Ritonavir (Norvir) 200mg

* Drugs not currently available in South Africa (Lucas, 2004; MIMS, 2005:318-322).

Table 1.2 Antiretroviral drugs under investigation for once daily dosing

Nevirapine (Viramune) 400mg
Lopinavir/Ritonavir (Kaletra) 6 capsules
Saquinavir 1600-2000mg + Ritonavir (Norvir)100mg
Indinavir (Crixivan) 800-1200mg + Ritonavir (Norvir) 200-400mg

(Lucas, 2004).

Virus resistance towards antiretroviral drugs can lead to elimination of whole classes of antiretroviral drugs as treatment options. It can also cause the spread of a resistant virus in a population, resulting in treatment naïve patients harbouring an already resistant virus. High levels of resistant virus is found in 15 - 24% of persons newly infected with HIV (Simoni, Frick, Lockhart & Liebovitz, 2002:431; UK Collaborative Group on Monitoring the Transmission of HIV Drug Resistance, 2001:1087). Limited treatment options and the emergence of treatment resistant viruses led to the recommendation that treatment should be delayed for as long as possible without causing the patient any harm (DHHS, 2004:8).

In a country such as South Africa where financial restraints are at the order of the day regarding even day to day living, antiretroviral therapy is often not a priority. If

antiretroviral options become too expensive due to repeated treatment failure, patients who initially were able to afford it will no longer be in a position to proceed with treatment. A patient's readiness to adhere to therapy should therefore be determined **before** treatment is prescribed. Wagner (2002:599) suggests that it is essential to establish reliable guidelines in order to establish such readiness. Currently no such standard guidelines exist. Underestimating patients' potential adherence can lead to withholding treatment unnecessarily, while overestimating potential adherence will lead to inadequate adherence and subsequent early emergence of virus resistance towards antiretroviral drugs. Not only can knowing a patient's adherence potential help the primary HIV care provider (PHIVCP) to decide whether to initiate antiretroviral therapy or not, but it can also give the opportunity to focus on adherence enhancing intervention in patients who need it most (Ibid, 599).

It is thus essential to enhance adherence to the optimum, in order to preserve treatment options and a resistant free population. Miller and Hays (2000:[7]) suggest that health care professionals should regard all patients to be potentially inadequate adherers, and offer intensive counselling and intervention to optimise adherence. It might be unwise to rush a patient into treatment before ensuring first that he/she truly understands what antiretroviral therapy would demand of them.

'All patients probably need continued counseling about the importance of adherence, regardless of their self-reported adherence, a clinician's assessment of their adherence, or their viral load' (Miller & Hays, 2000:[7]).

1.2 BACKGROUND TO THE PROBLEM

1.2.1 The significance of adherence

The success of antiretroviral therapy is related to the ability of antiretroviral drugs to suppress the Human Immunodeficiency Virus (DHHS, 2004:12).

'...adherence to treatment regimens is one of the cornerstones of adequate ART (Antiretroviral therapy – author's comment)' (Brigido, Rodrigues, Casseb, Oliveira, Rossetti, Menezes & Duarte, 2001:588).

A linear relationship between adherence to antiretroviral therapy and virus suppression was observed by several authors (See Figure 1.1). A significant correlation had been found between the increase in CD4 cell count for participants with an adherence higher than 95% (mean CD4 cell count increase of 83 cells/mm³) compared to those with an adherence less than 95% (mean CD4 cell count increase of 6 cells/mm³) (Bangsberg, Hecht, Charlebois, Zolopa, Holodniy, Sheiner, Bamberger, Chesney & Moss, 2000:360; Coetzee, Boulle, Hildebrand, Asselman, Van Cutsem & Goemaere, 2004:[3, 4]; Paterson, Swindells, Mohr, Brester, Vergis, Squier, Wagener & Singh, 2000:24-26).

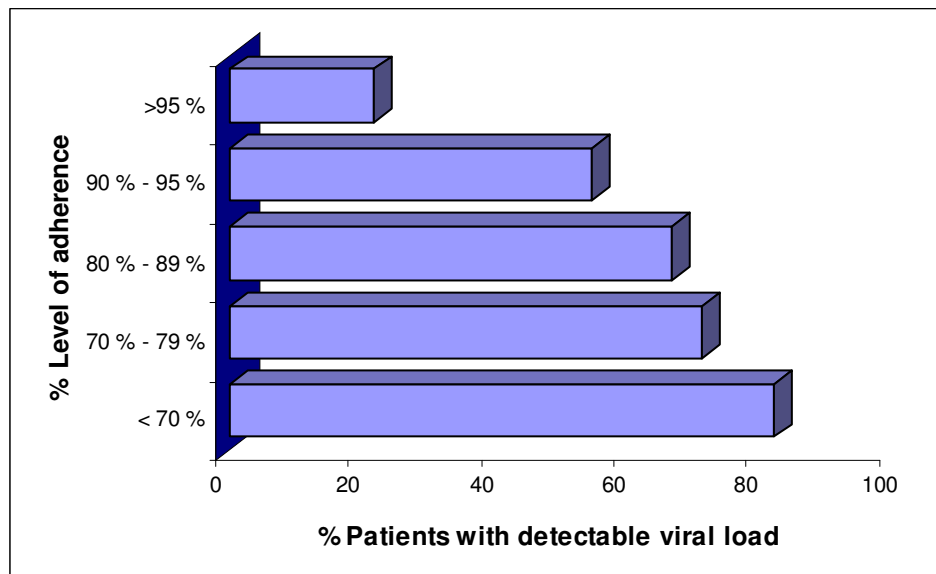


Figure 1.1 Viral load reflecting adherence (Adapted from Paterson *et al.* 2000:24).

The question may be asked as to what could be considered as adequate adherence.

For most chronic illnesses adherence in the range of 70% to 80% is considered to be acceptable. However, this is not true for antiretroviral therapy. Even short-lived interruptions in daily dosing regimens can cause the HIV to resume replication and develop resistance towards the antiretroviral drugs. Some authors suggested a threshold of 80%, as adherence below that level was associated with a dramatic decrease in virus suppression. This gave rise to the notion that adherence to antiretroviral therapy of higher than 80% to be acceptable. However, increasingly more authors suggest that adherence should be higher than 95% to achieve sustained virus suppression (Gross, Bilker, Friedman & Strom, 2001: [8]; Lyon, Trexler, Akpan-Townsend, Pao, Selden, Fletcher, Addlestone & D'Angelo, 2003:300; Miller & Hays, 2000:[7]; Paterson *et al.* 2000:25).

Recent studies demonstrated that the relationship between adherence to an antiretroviral regimen and the probability of developing resistance is a bell-shaped curve (*See Figure 1.2*). This implies that a low potential for resistance exists both with low (less than 70%) and high (higher than 95%) levels of adherence. However, sub-optimal adherence levels between 70% and 95% are associated with the highest probability to develop resistance as drug exposure is insufficient to achieve virus suppression but high enough to provide selective pressure. Moderate good, but not great adherers are therefore more at risk to develop resistance than poor or adequate adherers. When aiming to improve a patient's inadequate adherence, great care should be taken to avoid increasing adherence only enough to put the patient in this high risk group (Bangsberg *et al.* 2000:364; Hardy, 2003:19).

'... more adherence may not always be better than less adherence' (Gross *et al.*, 2001:[8]).

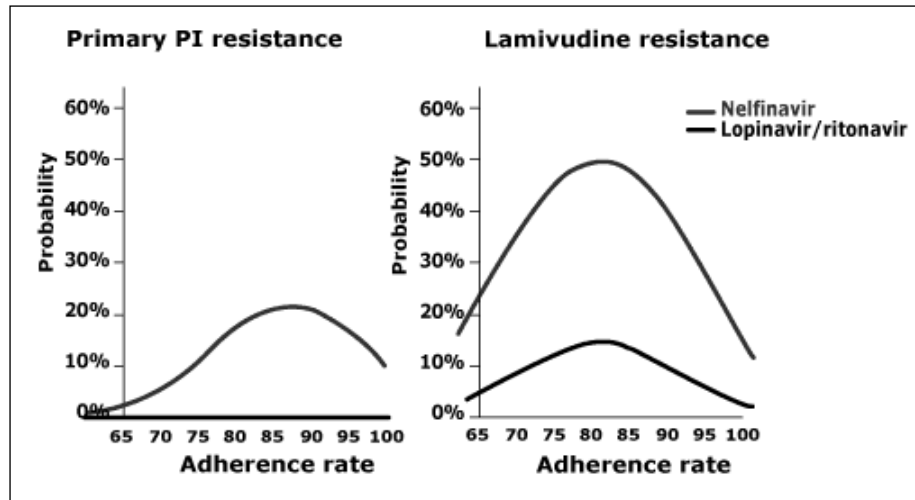


Figure 1.2 Relationship between suboptimal adherence and risk of resistance (Hardy, 2003:19).

An undetectable viral load is often seen as an indication of treatment success. However, this is not necessarily an indicator of sustained adherence. Patients with inadequate adherence may have undetectable viral loads, while patients with adequate adherence may display the opposite. This can be explained in the presence of pre-treatment virus resistance or poor metabolism of the antiretroviral drugs. Viral load suppression early in therapy is therefore an indication that the patient does not have resistant viruses. If a patient denies inadequate adherence, but viral suppression is not achieved at one month on therapy, virus resistance should be suspected (Gross *et al.* 2001:[7]).

The adherence required to achieve initial virus suppression may differ from the type of adherence necessary to maintain long-term virus suppression (Gross *et al.* 2001:[7]).

Highly Active Antiretroviral Therapy (HAART) has been associated with prolonged life expectancy due to a decrease in the emergence of opportunistic infections, reduced mortality rate and a reduction of overall health care costs of patients living with HIV. An increase in CD4 cell counts and the decrease in viral load are seen with adequate adherence. As the CD4 cell count of a patient increases, the patient's immune response against disease strengthens with a subsequent reduction in morbidity. The

opposite is, however, true for inadequate adherence (Paterson *et al.* 2000:25; Valenti, 2001:[3-4]).

1.2.2 Characteristics of adherence

Different main patterns of inadequate adherence were identified by Hill *et al.* (2003:521). The main patterns can also include different behavioural patterns. The identified patterns are:

1. Taking of medication very rarely (once a week or month)
2. Alternating between long periods of taking and not taking medication
3. Skipping entire days of medication
4. Skipping doses of the medication
5. Skipping one type of medication
6. Taking the medication several hours late
7. Not sticking to the eating or drinking requirements of the medication
8. Adhering to a purposely modified regimen
9. Adhering to an unknowingly incorrect regimen

A single patient may alternate between different main and/or behavioural patterns or display it simultaneously. One patient may, for example change the number of daily doses due to a belief that he/she is healthier and does not need that much medication, while another decreases the number of daily doses because there is never time in the middle of the day to take medication. The latter patient feels guilty and therefore increases the number of tablets in the remaining doses. Both change their doses, but for different reasons. The one believes it is the right thing to do while the other feels guilty because it is impossible to stick to the rules. It is thus extremely important to determine the patient's definition of adherence as it may differ from patient to patient (Ibid, 521).

In a different study aiming to understand the problem of adherence, three categories of inadequate adherence were identified by Donovan and Blake (Van Servellen, Chang, Garcia & Lombardi 2002:270).

1. **Erratic non-adherence** due to forgetfulness, being too busy or running out of medication
2. **Intentional non-adherence** where the patient deliberately decides not to take medication due to fear of side-effects or interference with lifestyle
3. **Unwitting non-adherence** where patients do not adhere to treatment due to language barriers and low-level health care literacy

(Laine, Newschaffer, Zhang, Cosler, Hauck & Turner, 2000:[5]; Van Servellen *et al.* 2002:270; Wagner, 2002: 602). Unwitting non-adherence may be particularly relevant to antiretroviral therapy in the South African context and may transpire from the results of this study.

A patient's understanding of the antiretroviral regimen is of the utmost importance. Determining this aspect will enable the health care provider to more accurately assess a patient's adherence behaviour. Different studies done amongst the urban poor and in a private practice setting, established that 13% to 14% of patients misunderstood their prescriptions. Misunderstandings and a patient's pattern of inadequate adherence, as described above, can easily be picked up by asking patients to describe their daily medication administering routine (Bangsberg *et al.* 2001:437, 440; Miller & Hays, 2000:[6]). A patient may for instance take medication three times a day, but not every eight hours.

Some sub-optimal behaviours are perceived as having a greater health risk than others. Most respondents believed that not taking medication for a few days is far more acceptable than not taking medication for several weeks or even months. The patient finds this behaviour more acceptable and would therefore not consider the not taking of medication for a few days as inadequate adherence (Hill *et al.* 2003:521-522).

1.2.3 Stumbling blocks to adherence

Numerous studies on adherence to therapy in chronic diseases attempted to determine the predictors of adherence. Demographic factors were found to have less impact on adherence than factors seldom assessed in clinical practice. These factors may include a patient's belief in the efficacy of the treatment, perception of the severity of the disease and social support. As a result different conceptual frameworks were developed to help health care professionals understand and study adherence and adherence behaviour. The Health Belief Model and the Theory of Reasoned Action are two such frameworks (Miller & Hays, 2000:[4]). According to these models a patient's intention to adhere to therapy is the strongest predictor of actual adherence. However, even good intentions have to cope with practical barriers such as side-effects (Brigido *et al.* 2001:591; Durante, Bova, Fennie, Danvers, Holness, Burgess & Williams, 2003:107-110; Singh & Squier, 1996:[4-5]).

Several factors associated with adherence to antiretroviral therapy were described by Wagner (2002:602-605) and Johnson, Catz, Remien, Rotheram-Borus, Morin, Charlebois, Gore-Felton, Goldsten, Wolfe, Lightfoot, Chesney and the NIMH Healthy Living Project Team, (2003:649-651). These factors included

1. Demographic data
2. Psychosocial data (including depression)
3. Active substance abuse
4. Social support
5. Attitudes and beliefs towards perceived treatment efficacy and self-efficacy
6. The ability to integrate the medication administering regimen into daily routine
7. Treatment characteristics like side-effects and the amount of pills to be taken daily
8. Patient-doctor relationship

Tsasis (2001:110-111) grouped these factors into four categories, namely:

1. Patient-related factors
2. Clinician-related factors
3. Regimen-related factors
4. Disease-related factors

Patient-related factors include a patient's perception of the benefit and side-effects of the particular treatment as well as knowledge regarding the diagnosis. The availability of support by significant others, social and emotional support provided by the healthcare team, forgetfulness, psychiatric conditions such as depression and socio-economic factors such as substance abuse and alcoholism also play a role in this category.

Clinician-related factors for instance clear and purposeful communication, support and encouragement, availability to answer questions and a non-judgmental attitude by the healthcare provider were identified to enhance adherence.

Regimen-related factors refer to the number of drugs, frequency of doses, ease of taking medication and the length of treatment.

Disease-related factors take account of factors such as disease severity and whether the disease is chronic or acute. This is influenced by a patient's beliefs regarding the disease (Tsasis, 2001:110-111).

Atreja, Bellam & Levy (2005:[4]) conducted a narrative review of current literature regarding proven interventions to enhance patient adherence. From the data gathered they developed a conceptual framework to implement critical adherence enhancing strategies.

They grouped the identified interventions into six categories by the mnemonic

SIMPLE.

1. **S**implifying treatment regimen characteristics
2. **I**mparting knowledge
3. **M**odifying patient beliefs
4. **P**atient communication
5. **L**eaving the bias; and
6. **E**valuating adherence

(Atreja *et al.* 2005:[1-3]).

A patient's ability to adhere to a specific medication regimen is greatly induced by the individual and his/her natural environment. For this reason the importance of multi-faceted and individual tailoring in contrast with single approaches cannot be stressed enough. Adherence interventions should address specific issues that hinder a patient to achieve or maintain adequate adherence (Johnson *et al.* 2003:654; Miller & Hays: 2000:[7]).

As the factors influencing adherence are intertwined, the approach to solve the problem of inadequate adherence should address different aspects at the same time.

1.2.3.1 Sustained adherence over time

Successful antiretroviral therapy requires a patient to consistently maintain adherence of at least 95% on a long-term basis. Concerns regarding patients' ability to consistently adhere to antiretroviral therapy were also raised (SAHIVCS, 2002:1, 6; Stone, 2001:865).

Several studies indicated that adherence may vary over time. As adherence tends to wane after the first month on antiretroviral therapy, special intervention around the end of the first month on therapy should improve long-term adherence (Gallant & Block,

1998:34; Gross *et al.* 2001:[7]).

Life events like a change in social structure or even holidays should be addressed specifically as it may entail a permanent or temporary lifestyle change that can influence adherence.

1.2.3.2 Mental health, cognitive status and substance abuse

According to Chesney (Stone, 2002:[2]) depression, active alcohol abuse, injection-drug use, as well as poor literacy are all positively associated with inadequate adherence.

People utilize different coping mechanisms in life. In coping with being HIV positive, a patient will probably revert to previously employed coping mechanisms, like the use or abuse of alcohol and recreational drugs. Power, Koopman, Vlok, Israelski, Stone, Chesney & Spiegel (2003:250) suggest that these factors should be identified and specifically addressed.

Cognitive impairment adversely affects a patient's ability to adhere to a medication regimen. This in turn furthers the disease progression and worsens the patient's cognitive functioning (Hinkin, Hardy, Mason, Castellon, Durvasula, Lam & Stefaniak, 2004:[6]).

From a group of 14 HIV patients who were also classified as drug dependant, Hinkin *et al.* (2004:[6]) found 13 of them to adhere inadequately to their antiretroviral treatment. One argument is that drug abuse induces HIV associated neuropsychological dysfunction. Drug abuse is, however, also often associated with a chaotic lifestyle contradictory to the structure that is necessary for adequate adherence. All factors posing a threat to adequate adherence should be stabilized before a patient starts on antiretroviral therapy. This is the preferred course of action

compared to withholding treatment. The existence of these factors should also serve as an indication for more individualized intensive support to achieve and maintain adherence (Stone, 2002:[2]).

1.2.3.3 Social support and adherence

The need for social support correlates positively with acknowledged inadequate adherence. No correlation was, however, uncovered between inadequate adherence and **actual** support. The need for support from a significant other, an information enhancing relationship, an emphatic listener or a spiritual relationship were factors identified as having an influence on adherence. A lack of self-efficacy and depressive symptoms may induce the need for support. Patients who believe they can take their medication correctly have better adherence towards medication regimens. In contrast patients suffering from depression display a lack of energy to comply with difficult medication regimens. This can be attributed to poor appetite and a loss of hope (Simoni *et al.* 2002:436-437).

A positive correlation between perceived social support by a partner and adherence had been found in a study conducted by Power *et al.* (2003:250). However, perceived support from family and friends do not have the same influence on adherence behaviour. This may be due to the more intimate nature between partners when compared to the relationship between friends. Involving a partner in the treatment program can thus be an effective tool towards enhancing adherence.

Contrary to the aforementioned findings being single, living alone or having a small household are positively associated with adequate adherence. Although these situations are linked to less social support these patients may have less social stress and responsibilities. Larger households or having a partner and maybe a family interfere with adherence by adding stressors and responsibilities that may distract a patient from being adherent (Wagner, 2002:605).

1.2.3.4 Medical treatment and healthcare provider related characteristics

The more complex an antiretroviral regimen and the larger the quantity of pills, the poorer adherence will be. This hypothesis was tested in two groups by Stone, Hogan, Schuman, Rompalo, Howard, Korkontzelou and Smith (2001:[7-9]). In the first group the participants took one or two doses per day and 86% participants could correctly report their dosing instructions. In the second group at least one medication required administering on an empty stomach and at least one medication was administered three times a day. Of these, only 28% of participants could report their dosing instructions correctly. It is important to remember that simplifying an antiretroviral regimen will not create adherence where none was present before, but will only improve adherence of those who are already highly motivated.

Contrary to these findings Wagner (2002:603-604) found that the number of pills per day, the length of time of current treatment and regimen complexity were not associated with the degree of adherence.

Current symptoms are associated with a decline in adherence when measured by self-report, medication diaries and electronic monitoring. This also applies to symptoms perceived by patients to be caused by the antiretroviral drugs. Adherence to a treatment regimen may be particularly challenging to patients struggling with physical symptoms and not feeling well. This can be of particular concern in pregnancy where women are expected to adhere to antiretroviral therapy whilst struggling with symptoms like nausea. In contrast, patients who do not experience any symptoms may perceive themselves as less vulnerable and therefore less motivated to adhere to their treatment. In this instance the presence of symptoms may heighten a patient's perceived severity of the disease and act as an adherence motivator. Furthermore, factors such as disease progression and the most recent CD4 cell count and/or viral load results do not relate to adherence (Singh & Squier, 1996:[5]; Wagner, 2002:603-604).

In a study conducted by Van Servellen *et al.* (2002:271, 275-277), factors leading to inadequate adherence to antiretroviral therapy were divided into **individual level** and **system level** factors. According to this study patients have little or no control over system level factors like patient-provider relationship, other health care provider characteristics and social characteristics such as the availability of transport. To elaborate on these findings, several studies indicate that a trusting relationship between the patient and the healthcare provider leads to increased adherence. The physician-patient relationship in particular exerts a strong influence. Dissatisfaction with medical care and a feeling of being “left out” with regard to treatment decision-making, both reduce adherence. However, in a collaborative relationship where patients feel in control of their disease, both patient satisfaction and adherence increased. This relationship should be based on trust and respect. In addition Coetzee *et al.* (2004:[5]) found that continuity of care and knowledge regarding each patient were considered to be important.

A study done by Douglass, Sowell and Phillips (2003:12-18) amongst women with the aim to understand the importance of the relationship between the patient and the primary HIV care provider, revealed the following information:

Table 1.3 Evaluation of the relationship between the primary health care provider (PHCP) and the patient

Item	Agree %	Disagree %
My PHCP always tells me the truth	95.0	5.0
I worry about my PHCP keeping information about me confidential	82.5	17.5
My PHCP tries to give me the best care and treatment available	91.6	8.4
I can trust my PCHP to explain my treatment so that I can understand	91.2	10.8
There are some things I don't feel comfortable telling my PCHP	72.5	27.5
I take my PCHP's advice about treating symptoms of my HIV	94.9	5.1
My PHCP is likely to report me to the Department of Family Services or other authorities if I'm not careful about what I tell him/her	81.4	18.6
My PHCP gives me accurate information about my health care treatment	91.7	8.3
Sometimes I think my PHCP doesn't tell me everything about my health	82.5	17.5
I trust what my PHCP tells me	90.0	10.0
I can talk to my PHCP about anything that concerns me	82.5	17.5
My PHCP trusts me	82.9	17.1

(Douglass *et al.* 2003:[12, 18]).

These findings underscore Peplau's theory (Douglass *et al.* 2003:[12]) that the relationship between a patient and the health care provider has a substantial influence on a patient's potential to learn and set health goals for themselves. This underscores the importance of communication and the identification of barriers to communication and health-seeking behaviour.

Increased medication adherence was reported where treatment regimens were individualized. In order to achieve this goal it is important to perform an individual assessment of adherence and the barriers thereof for each patient (Douglass *et al.* 2003:[12]; Tsasis, 2001:111).

1.2.3.5 The impact of health literacy on adherence

Knowledge regarding the effect of antiretroviral therapy on viral load is a greater predictor of adherence than a patient's level of education. In comparing adherence related education provided at an adherence clinic and the same education delivered by a primary physician, the group attending the clinic showed better adherence. The group receiving their information from the clinic displayed 100% virus suppression at week 16, compared to the 70.6% virus suppression in the group receiving information from their primary physician (Durante *et al.* 2003:112; Rathbun, 2004²). This study also implies that the manner in which information is conveyed play an important role.

Lee, Arozullah & Cho (2004:[3]) proposed a framework to explain the connection between health literacy, health status and the utilization of health services. The framework consists of four interlinked factors, namely:

1. Disease knowledge and self-care
2. Health-risk behaviour
3. Preventative care and routine physician visits
4. Adherence to treatment

² Poster presented at the 11th Conference on Retroviruses and Opportunistic Infections, San Francisco, 8-11 February, 2004

The framework suggests that persons with lower health literacy perform worse in all four the above mentioned categories. The less knowledge a person has regarding health and disease, the more likely he/she is to overlook important warning signs. This leads to fewer primary care and preventative health care visits but prolongs hospitalization and utilization of other secondary care facilities (Lee *et al.* 2004:[3]).

Reduced utilization of health services may be due to difficult communication between healthcare professionals and health or disease illiterate patients. Respondents with a low level of health literacy tend to report their health as poor. Poor health literacy also leads to misconceptions (Lee *et al.* 2004:[3]). Common examples are, for instance myths that antiretroviral therapy will prevent HIV transmission or that antiretroviral therapy is lethal.

People with a low health literacy level are on average less capable of caring properly for themselves and may therefore display a higher level of risk behaviour. Social and structural support may, however, have a moderating effect.

As patients become less ashamed of being illiterate regarding their health problems they set out to seek information by other means. However, the opposite is also true.

This may strongly indicate that a specialized adherence facility should provide patients with adequate information and support. Information should be imparted on a need-to-know basis to increase effective learning. Health care providers should, however, regularly assess patients' level of knowledge and information needs. Information should then be offered accordingly.

'The general wisdom has been that in order to be effective, interventions to improve adherence to HAART need to be individualized, multifaceted, and repetitive' (Stone, 2002:[3]).

1.2.3.6 Adherence and demographic data

The assumed inability of poor people to adhere to lifelong antiretroviral therapy in resource-limited countries was contradicted by research conducted in the Khayelitsha Township in South Africa, by Coetzee *et al.* (2004:[4]). Data acquired from this study indicated that through careful patient preparation, viral suppression comparable to that seen in developed and developing countries, can be achieved.

Although several studies were able to associate female sex, a younger age and specific race groups with adequate adherence, just as many were not able to draw this correlation. Some even found contradictory evidence (Hinkin *et al.* 2004:[4]; Johnson *et al.* 2003:649-651; Kemppainen, Levine, Mistal & Schmidgall, 2001:123-125; Laine *et al.* 2000:[5]; Wagner, 2002:603).

In a study assessing the variables and prevalence of factors associated with adherence to antiretroviral therapy, black HIV positive patients were poorer adherers. These findings were independent of drug use, education, social support, employment, history of opportunistic infections and depression (Singh & Squier, 1996:[5]).

Language difficulties and cultural differences probably contributed to the inadequate adherence found amongst pregnant women in a New York study. In this study adherence to therapy among Black and Hispanic women were nearly 20% lower than for White women (Laine *et al.* 2000:[5]).

The stigma surrounding HIV often labels women as unworthy and immoral, and devalue them as mothers, sisters and wives. Women also fear losing their children when admitting or proclaiming that they are HIV positive. These beliefs prevent them from seeking medical care and contributes to inadequate adherence (Trzynka & Erlen, 2004:[7]).

Stigma also isolates woman from social and financial support. This can not only

interfere with adherence, but can even prevent her from accessing antiretroviral therapy altogether.

Caretaking responsibilities, pregnancy and motherhood may distinguish adherence problems experienced by women from those experienced by men. During pregnancy a patient may deliberately choose not to adhere to antiretroviral therapy in fear of what the medication can do to the unborn child. Pregnancy also contributes its own challenges, such as nausea, that can be aggravated by antiretroviral therapy (Laine *et al.* 2000:171; Mellins, Kang, Leu, Havens & Chesney, 2003: 413-414; Tsisis, 2001:110; Van Servellen *et al.* 2002:279).

Tailoring an adherence program to be sensitive to cultural and socio-economical factors is essential if greater adherence to antiretroviral therapy is to be expected (Kempainen *et al.* 2001:118; Stone, 2001:869-870).

1.2.3.7 HIV prevalence and demographic data in South Africa

The Nelson Mandela/Human Sciences Research Council executed a survey including all race, gender and age groups. The HIV incidence amongst Blacks is higher than in the other three race groups, while the incidence is lowest amongst Indians. As there are no biological evidence that specific races has a higher or lower risk for contracting HIV, the behavioural variables specific to each ethnic groups should be identified (Connolly, Colvin, Shishana & Stoker, 2004:778-780).

Culture is not exclusive to a specific ethnic group. Being part of a specific ethnic group is not necessarily an indication of the traditions a person will conform to. Each patient should therefore be assessed individually for beliefs and traditional behaviour that may interfere with adherence. South Africa is a multicultural country where a diversity of cultures, traditions and beliefs are intertwined rather than detached.

Women of all race groups are at a significantly higher risk to acquire HIV, than men. However, amongst the different race groups, only a statistical difference exists between Black women and Black men (Connolly *et al.* 2004:778).

The HIV incidence amongst women globally is mounting. In sub-Saharan Africa women make up 57% of HIV infected adults and more than three-quarters of infected youths are women (See Figure 1.3). According to the UNAIDS Epidemic Update, this is likely due to gender inequality and violence against women. In many countries women are expected to know little about sex and sexuality and are therefore also poorly educated regarding the transmission of HIV. Without this knowledge and the power to exercise it, women are especially vulnerable to contract HIV (UNAIDS/WHO, 2004: 4, 8-9).

The same factors act as vehicle for HIV transmission amongst women. Poor education and a lack of decision-taking power, may also influence a women's ability to adhere to antiretroviral therapy.

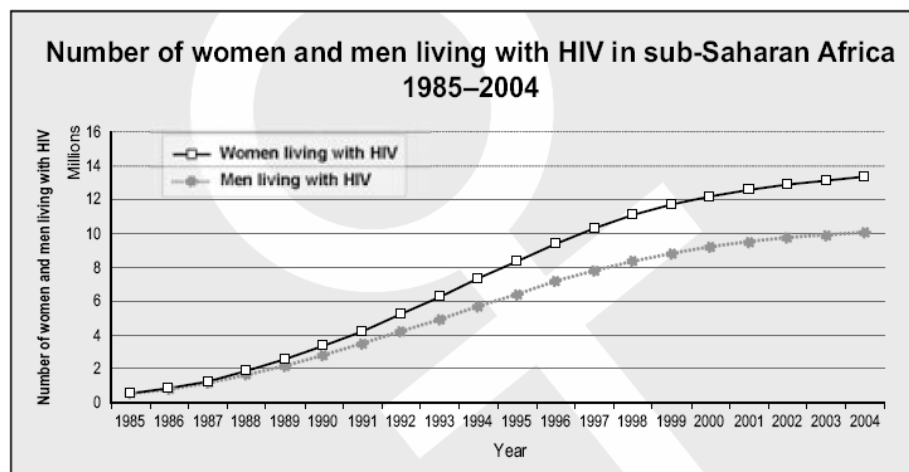


Figure 1.3 Number of women and men living with HIV in sub-Saharan Africa (UNAIDS, 2004:8).

1.2.4 Measuring adherence

Different measuring tools to determine adherence are currently available. There are, however, no golden rule or standard as researchers use different measuring instruments. Comparing research results remain a difficult task. Every available tool either over- or underestimate adherence. In order to compensate for this it is thus advisable to use a combined approach (Miller & Hays, 2000:[2-3]; Turner, 2002:S144; Stone, 2002:[3-4]).

In addition to measuring recent adherence, it may also be important to determine cumulative adherence. Virus resistance towards antiretroviral drugs is the result of continued inadequate adherence and might not be reflected in the adherence reported for the recent past. Another issue addressed by Sethi, Celentano, Gange, Moore and Gallant (2003:[6-7]), focused on the reversibility of previously inadequate adherence. Knowledge regarding the long term effect of temporary inadequate adherence is crucial in the development of an instrument to measure cumulative adherence. If previously inadequate adherence is reversible it will give patients and healthcare workers a new goal to work towards.

Patient self-report tends to overestimate patients' adherence when compared to more objective means of measurement such as pill counts and electronic monitoring. This can be explained by the inclination of patients to tell the healthcare worker or doctor what they believe to be acceptable. This may not always reflect actual adherence. When patients alter their treatment regimen, on purpose or unknowingly, they often do not classify themselves as 'not adhering' to their treatment. Some patterns of inadequate adherence are perceived as harmless by some patients. However, a patient who reports poor or inadequate adherence seldom lies. Furthermore, a patient who admits to inadequate adherence may be more responsive to specific adherence enhancing intervention than a patient who denies it (Hill *et al.* 2003:523; Liu, Golin, Miller, Hays, Beck, Sanandaji, Christian, Maldonado, Duran, Kaplan & Wenger, 2001:[8]; Miller & Hays, 2000:[2]; Turner, 2002:S144).

Several studies were able to correlate self-reported adherence with viral load suppression while others detected no correlation. Using self-reported adherence in isolation to determine adherence should be avoided (Bangsberg *et al.* 2000:362; Liu *et al.* 2001:[8]; Walsh, Mandalia & Gazzard, 2002:[7-8]).

The self-report questionnaire is currently the most widely used of all available methods. Some of the reasons for this method may be the relative low cost involved, convenience and applicability in daily clinical practice as well as research settings. The self-report questionnaire, when carefully developed, could be a valuable method to collect information regarding adherence (Stone, 2002:[4]; Vincke & Bolton, 2002:493-494; Godin, Gagné & Naccache, 2003:329-330).

When using self-report adherence tools, the patients need to be assured that they will not be penalized for the answers that they supply. It should be stressed that accurate and truthful answers will provide the healthcare provider with insight into the patients' adherence. Audio-computer assisted self-reporting appears to be helpful as the patient tends to be more honest regarding sensitive topics. It may therefore be helpful if someone other than the primary healthcare provider obtains this information (Turner, 2002:S144; Walsh *et al.* 2002:[3]).

Self-reported adherence should be limited to the past four days as it may be difficult to recall adherence over longer periods of time. Special attention should, however, focus on weekends and holidays as it tends to be a difficult time for treatment adherence due to interruptions in the daily routine (Turner, 2002:S144).

Patients may display artificially enhanced adherences in the days directly prior to visiting a doctor. It can be caused by their increased awareness of the upcoming consultation or by a desire to impress or please the healthcare provider. Patients usually make their own appointments and know when their next consultation will be.

Precise measuring techniques to enhance a patients' memory regarding adherence

can improve the efficacy of adherence questionnaires. Limiting adherence recall period to the last few days, or providing a card with pictures of all the available antiretroviral drugs on the market, can help patients to recognize and name their drug regimen (Godin *et al.* 2003:326).

According to Hill *et al.* (2003:520-523) self-report will be more reliable if surveys take into account a patient's definition and patterns of adherence. Interviews focused on self-reported adherence provide information about patient adherence and adherence barriers from the patient's social perspective. Information provided by exploring the rationale behind these patterns should be helpful in predicting and improving adherence through intervention.

These measurements should be standardized and performed repeatedly to allow for evaluation (Stone, 2002:[4]).

The pill identification test requires patients to identify the pills that they take from a board displaying two similar pills for each antiretroviral drug. A high level of identification has been associated with better adherence (Turner, 2002:S143).

With **medication diaries** the patient records every dose taken. This may have value in determining adherence. Patients may cheat by filling in doses not really taken, or forget to fill in the diary. Response to this measuring tool had been poor in the ADEPT study. Only 25% patients returned their diaries as instructed. This method overestimates adherence and correlates with adherence measured with standard self-report (Miller & Hays, 2000:[2]; Wagner, 2002:602-603).

Pill counts are a more accurate measure of adherence. This method is, however, time-consuming and patients may forget to bring their pills along. Whether forgetting to bring pill containers along can be regarded as part of inadequate adherence is still uncertain. This method may be perceived as intrusive or judgmental by the patient and

thus harming the patient-healthcare provider relationship. Determining the date that the current prescription was started may also be difficult with patients who combine their medicine into one container, or who use different formulations of the same drug. Some patients may tend to remove excess pills if they know their pills will be counted (Miller & Hays, 2000:[2-3]; Turner, 2002:S144; Walsh *et al.* 2002:[8]).

The **prescription refill data system** can be useful in determining whether a patient refills the prescription in time to continue uninterrupted treatment. This method does not take into account a patient refilling a prescription at another facility. However, should this data be retrieved reliably, it correlates with a decrease in virus levels (Maher, Klimas, Fletcher, Cohen, Maggio, Triplett, Valenzuela & Dickinson, 1999: [3-5]; Turner, 2002:S144-145).

Electronic monitoring systems can also be used. An electronic chip is put into the bottle cap. Each time the bottle is opened it records information like the date and time. Researchers or service providers can download the data from time to time for evaluation. This is a more objective measure of treatment adherence. Electronic devices are, however, expensive and do not take into account patients who use pillboxes and remove several doses at once. Adherence for those patients may therefore be underestimated (Liu *et al.* 2001:[7-8]; Miller & Hays, 2000:[3]; Turner, 2002:S144-5; Wagner, 2002:602-603; Walsh *et al.* 2002:[6]).

Another valuable asset of electronic monitoring is the possibility of measuring intervals between doses. This can provide information regarding the 'when' of adherence and not only the 'how much' (Liu *et al.* 2001:[6]).

This feature can allow health care providers to identify patterns of inadequate adherence and thus develop their adherence intervention strategies accordingly.

An improvement of actual adherence has been associated with the use of electronic monitoring devices. This may have been attributed to patients' feeling that they are being observed (Stone, 2002:[3]).

Laboratory markers are only markedly sensitive and can be confounded by pharmacokinetic factors such as sub-optimal drug absorption or drug-to-drug interaction. These factors may imitate inadequate adherence. Determining drug levels of antiretroviral drugs reflect only adherence within the previous 24 hours and are expensive. Patients can manipulate test results by deliberately taking medication shortly before scheduled blood testing (Miller & Hays, 2000:[3]).

A correlation between adherence to zidovudine or stavudine, and an increase in Mean Corpuscular Volume has been identified. This marker is, however, limited to the aforementioned two drugs, and it is assumed that the patient takes the other drugs in the regimen with the same adherence than taking zidovudine and/or stavudine (Romanelli, Empey & Pomeroy, 2002:409-411).

Providers estimating a patients' adherence have been shown to be especially inaccurate. This tendency has also been found in similar studies conducted on other chronic diseases. According to a study conducted by Paterson *et al.* (2000:26-27), nurses incorrectly predicted adherence for 30% of patients, while doctors predicted 41% incorrectly. Bangsberg *et al.* (2001:439-440) found that provider-estimate of adherence correlates with patient self-report through structured interviews. Both, however, overestimated adherence when compared to unannounced pill counts. Patient self-report was more sensitive, specific, and predictive than provider-estimates.

Directly administered antiretroviral therapy (DAART) is based on the Directly Observed Treatment (DOT) model for tuberculosis. The aim of DOT is to improve clinical outcome by improving adherence, preventing spread of tuberculosis and to

reduce the risk of emergence of drug resistance. Most studies were conducted in settings where there is frequent interaction between healthcare providers and patients, for example prisons. In this controlled environment, Fischl, Castro and Monroig proved DAART to be superior to self-administered treatment (Lucas, Flexner & Moore, 2002:527-529).

These findings could, however, not be duplicated in a study conducted by Wohl, Stephenson, Golin, Kiziah, Rosen, Ngo, Liu & Kaplan (2003:[5]) among prison inmates. This study also compared DAART with self-administrated therapy (SAT) and revealed no significant difference in adherence between the two methods. In addition, the respondents indicated that standing in line to receive their medication compromise confidentiality.

Antiretroviral therapy is prescribed for life and doses should be administered more than once daily. DAART may therefore be largely unfeasible as an outpatient strategy. If DAART could be utilized successfully the questions still remains: For how long a period of time should DAART be exercised to impact on adherence? The concern exists that DAART may not be acceptable to patients due to the suspicion of inadequate adherence implied by the health care provider. It may reduce the trust between the health care provider and the patient that is an essential part of adherence (Lucas *et al.* 2002:530).

Stone (2002:[3]) suggested that DAART or DOT could be used as a medication-taking training period for patients at high risk for inadequate adherence.

1.2.5 Comparing different measuring tools

When using 95% as the cut-off point for adequate adherence the method in use to measure adherence should be taken into consideration. The different measures available differ in specificity and sensitivity.

With adherence greater than 95% as established by electronic devices, virus suppression correlated with adherence. Adherence as measured with an electronic device estimates adherence lower than when measured by self-report (Paterson *et al.* 2000:24-25).

In a study conducted by Bangsberg *et al.* (2000:360) self-report and unannounced pill counts were compared to electronic medication monitoring. Virus suppression was better correlated with pill counts and the use of electronic devices than with self-report.

1.2.6 Treatment of HIV patients in South Africa

In April 2002, the Cabinet of South Africa reiterated its commitment to an HIV and AIDS Strategic Plan. This plan envisioned that by the end of 2004 a minimum of one service point in every health district would be operational. This will grow over the next four years until HIV positive people can access quality care at their local municipalities (South African Government, 2003:13-14).

Facilities that met with the basic criteria for accreditation would then start admitting patients for HIV testing, assessment of immune status, viral load and the clinical stage of infection. It will also provide interventions to delay progression of the infection such as nutritional supplements, complementary and traditional medicines and step-down facilities (Mohapeloa, 2004b).

People who qualify for, and request antiretroviral treatment will undergo a treatment literacy program to ensure that they adhere to the treatment requirements.

Currently, only a few patients access antiretroviral therapy through the public health system. The stigma of HIV and its treatment induced by the prolonged debate in the media and on government level, regarding the relation between HIV and AIDS, as well as the emphasis on antiretroviral drug toxicity and efficacy, is but one of many possible explanations. Ignorance on the side of patients regarding treatment and treatment sites may also play a role.

At the end of December 2004, 129 treatment sites had been accredited to issue antiretroviral drugs and 32 302 patients received antiretroviral therapy in the public sector from these accredited sites. This implicated that the government did not reach its target of 53 000 people on treatment in March 2004. This target was subsequently revised to 53 000 people on antiretroviral therapy by March 2005 (Mohapeloa, 2004a; HIVAN, 2005; See Figure 1.4, See Appendix A).

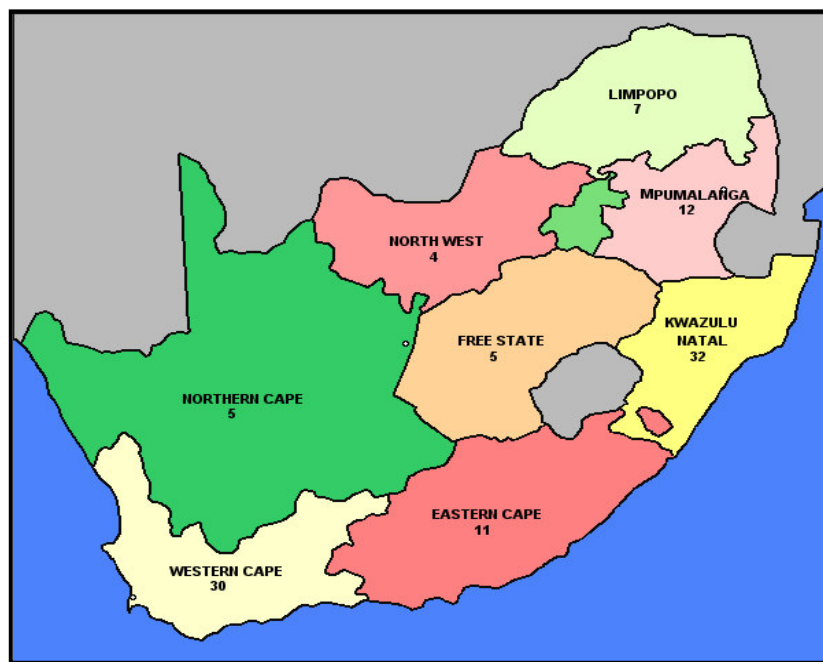


Figure 1.4 Number of accredited government treatment sites in South Africa according to provinces (See Appendix A)
(South African National Department of Health, 2004).

In a statement issued on April 16th 2004, the South African Department of Health expressed its concern regarding the readiness of these treatment sites. Several gaps

were identified and efforts are being made to address these deficiencies and to strengthen the national health system as a whole (Mohapeloa, 2004a).

Most South Africans on antiretroviral therapy make use of their medical aid benefit or private funding to access treatment in the private healthcare sector. A selected few companies provide HIV care to their employees and this usually includes antiretroviral therapy. International sponsors also provide HIV care to a limited number of HIV positive patients, while a number of patients access antiretroviral therapy through clinical trials.

1.3 PROBLEM STATEMENT

Inadequate adherence to antiretroviral therapy leads to treatment failure and the emergence of resistant viruses with eventual exhaustion of treatment options. Adherence is currently the only factor that can be controlled to delay the development of virus resistance. It is therefore imperative to develop measures to optimally enhance adherence as well as to manage factors that adversely influence adherence. In South Africa, patients access antiretroviral therapy through the public and private healthcare sector. A significant number of patients make use of the private healthcare facilities.

Although an abundance of literature exists on factors that influence adherence, little literature could be found that is specific to the South African context, and more specific to patients that can afford to make use of private healthcare facilities.

As women are more at risk to acquire HIV, and according to statistics, Black women in particular, it is logical to conclude that more black women will enter treatment with antiretroviral drugs. They are thus a large target group to consider when addressing issues influencing adherence. As there may be factors specific to a race group

facilitating the spread of HIV, there may also be specific factors influencing adherence to antiretroviral therapy.

Mental health, cognitive function and substance abuse will not be specifically addressed in this research, as it is already thoroughly researched and known to impact adherence negatively.

Existing international literature displays controversy on many factors identified in studies. It is thus essential to investigate the South African context in order to identify similarities and exceptions to the existing body of knowledge. Only then can healthcare professionals start implementing measures to improve adherence and to prevent worsening of existing adherence problems.

To conclude, a statement by Sorensen, Mascovich, Wall, DePhilippis, Batki & Chesney (1998:[2]) state that:

‘Adherence reflects an attitude that a patient is empowered by a medication regimen, rather than simply complying with the wishes of medical staff’.

The following research question is asked

What are the factors associated with optimal and inadequate adherence to antiretroviral therapy for the treatment of HIV infected women attending an urban private healthcare facility?

1.4 THE AIM OF THE STUDY

The aim of the study is to determine all factors helping the participants to adhere to antiretroviral therapy, as well as all factors hindering them to adhere to antiretroviral therapy. The study is limited to the female patients who attend a selected private urban healthcare facility.

1.5 OBJECTIVES OF THE STUDY

The objectives of the study are to determine all factors that have an influence on patients' adherence to antiretroviral therapy. These factors will then be categorized as:

1. Factors that inhibit or may inhibit adherence to antiretroviral therapy
2. Factors that enhance or may enhance adherence to antiretroviral therapy

All the factors resulting from this study will be compared to the existing body of knowledge to identify similarities, differences and suggestions for further investigation on this topic.

1.6 PROPOSALS

Proposals in case studies, such as the proposed study, direct attention to what is investigated within the scope of the study. It relates directly to the research question, aims and objectives of the research (Yin, 2003:22).

The researcher assumes that by identifying the factors that enhance or hinder adherence to antiretroviral therapy, recommendations can be made to support patients on antiretroviral therapy. These recommendations will empower healthcare providers to assess patients' readiness to commence treatment as well as to better anticipate or identify periods of poorer adherence amongst their patients. When knowledgeable about aspects that can influence patients' adherence, self-reporting, interviews or questionnaires to determine adherence can be more specific and sensitive.

This information can help patients to anticipate possible obstacles and manage it in advance, so as not to interrupt their optimal adherence. Patients struggling to achieve optimal adherence can also benefit from this information as they can learn from

others' experience. The study is focused on female patients who attend a selected private urban healthcare facility as the researcher believes that factors such as culture, sex and social-economic status have an influence on adherence to antiretroviral treatment.

1.7 SIGNIFICANCE OF THE STUDY

The study is significant as it aims to identify factors that influence adherence to antiretroviral therapy amongst women in an urban private healthcare facility.

It transpired in the literature that adherence to antiretroviral therapy can be positively or negatively influenced by numerous factors. These factors are not constant in their influence and therefore a specific factor can enhance adherence in one setting, while inhibiting it in another. Factors can be disconnected or intertwined. In this study it will be determined whether the same factors that influence other populations as described in the literature, also have an influence on the above mentioned population. New factors may also come to light and will thus be added to the body of knowledge.

Adherence to antiretroviral therapy differs in some aspects from adherence of medication to other chronic diseases. It is important to identify these differences as it can have a profound influence on adherence to therapy. Stigma surrounding an HIV diagnosis creates a cascade of difficulties regarding adherence. Most patients need to keep their treatment a secret as none or only a few people are aware of their HIV positive status. As a rule they are not prepared to disclose their status for fear of social and emotional rejection. This implies that patients have to take their medication in privacy. In a busy work environment this can cause practical problems when it is time to take medication but circumstances does not allow for privacy.

Most other chronic diseases are not subjected to the strict adherence requirements of

antiretroviral therapy. Few drugs used in the treatment of other chronic diseases run the risk of developing resistance. Furthermore, most chronic diseases have more treatment options available than those for antiretroviral therapy. Antiretroviral drugs are highly debated in the public media, but the information is sometimes flawed. This leads to the formation of misconceptions and rumours that are not easily rectified. Many patients developed an unrealistic fear of antiretroviral drugs because of these fabrications. Even the origin and cause of HIV is highly debated and can lead to patients not accepting their diagnosis or the treatment thereof.

Women have special needs and responsibilities that may interfere with adherence to antiretroviral therapy. Many are mothers and have to take care of their own, as well as other family members' needs. This is often besides having a career of her own. In spite of all the progress in recent years, many women are still subjected to social, financial, sexual and political inequality. As the HIV infection rate amongst women gradually increases over the years, it is logical to assume that the same factors that make women vulnerable to HIV infection may also influence their adherence.

1.8 DEFINITION OF TERMS

Adherence is the degree to which a person follows the instructions regarding the administering of medication. Adherence to antiretroviral therapy exceeding 95% is associated with sustained virus suppression (Tsisis, 2001:109-110; Wilson, Naidoo, Bekker, Cotton & Maartens, 2002:330).

ART is the acronym for Antiretroviral Therapy and refers to all drugs developed to prevent the Human Immunodeficiency Virus from replicating. These drugs suppress the HIV but are not able to destroy it (Wilson *et al.* 2002:332).

CD4 cell Count refers to the number of CD4+T-lymphocytes in the bloodstream. These cells play a role in the immune system and a decrease in its numbers are associated with immune suppression. The CD4+T-lymphocytes are directly and indirectly destroyed by HIV. The CD4 cell count is usually expressed in cells/ μ L, but can also be expressed as a percentage of the normal value (Wilson *et al.* 2002:46).

DAART is an acronym for Directly Administered Antiretroviral Therapy. This model of administering antiretroviral therapy is based on Directly Observed Therapy (DOT), used in the treatment of tuberculosis. Every dose of medication to be taken is observed by another person, usually a healthcare worker (Lucas *et al.* 2002:527).

DOT is an acronym for Directly Observed Therapy. This method of administering medication was used with great success in tuberculosis treatment (Lucas *et al.* 2002:52).

FDA refers to the United States Food and Drug Administration. The FDA is an agency ensuring the safety and effectiveness of all medication and food on the American market (FDA, 2005).

HAART is an acronym for Highly Active Antiretroviral Therapy. HAART consists of a combination of three different antiretroviral drugs. HAART is associated with less emergence of virus resistance when compared to the use of only one or two antiretroviral drugs in therapy (Wilson *et al.* 2002:332).

HIV is the acronym for Human Immunodeficiency Virus. Infection with the HI virus eventually wipes out the body's immune system and the person becomes vulnerable to infections and carcinomas. As the body is no longer able to defend itself, an HIV infected person usually dies from an opportunistic infection or carcinoma (Wilson *et al.* 2002:3).

Mutations develop when the virus makes mistakes when replicating itself. Because of its poor proofreading ability, the faulty new cells are also released into the bloodstream. These mistakes allow the virus to change and escape the pressure exerted by the antiretroviral drugs (Hoffmann, Rockstroh & Kamps, 2005:71, 170, 311, 314).

Pill burden refers to the number of pills a patient has to take per day. A greater quantity of pills is associated with inadequate adherence (Bartlett, 2005:71; Hsu, 2005).

Poor adherence is defined by Sethi *et al.* (2003, [6-7]) as adherence below 70%. A distinction between poor and sub-optimal adherence is necessary as they are associated with different levels of risk for the emergence of resistance.

Sub-optimal adherence is defined by Sethi *et al.* (2003:[6-7]) as 70% - 89% adherence. A distinction between poor and sub-optimal adherence is necessary as it is associated with different levels of risk for the emergence resistance.

Step-down facilities are specialized facilities geared to care for people with long-term or chronic health problems. It also includes frail care and rehabilitation.

A traditional healer is usually a woman and is also know as a *songoma*. They practice a traditional medicine that entails the throwing of bones and consulting ancestors to identify the cause of illness. They treat their patients with herbal remedies (Webb, 1997:253).

Viral load refers to the concentration of free viruses detectable in blood. The viral load is expressed as copies/mL or \log_{10} . A patient's viral load should be less than 50 or 400 copies/mL (depending on the test used) after four to six months on antiretroviral therapy. This is an indication of treatment effectiveness (Wilson *et al.* 2002:44-45).

Virus replication takes place when the HI virus produces copies of itself. The virus cannot replicate on its own and therefore needs a human cell, like the CD4 cell, for this function.

Virus resistance emerges when some of the mutations created during virus replication are resistant towards the antiretroviral drugs. The specific antiretroviral drugs will then no longer be effective against the specific strain of mutation (Hoffmann *et al.* 2005:71, 157, 169).

1.9 OUTLINE OF THE STUDY

The description of the research, its findings and recommendations are covered in:

Chapter 1: Introduction and orientation to the study

Chapter 2: Methodology of the research, the research site and biographical data of the participants

Chapter 3: Presentation and discussion of data

Chapter 4: Conclusions, recommendations and suggestions for further study

References

Appendices

1.10 CONCLUSION

In this chapter the significance of optimal adherence to antiretroviral therapy has been discussed. Inadequate adherence gives rise to emergence of virus resistance towards antiretroviral drugs. This sequentially leads to the development of a resistant population and exhaustion of treatment options.

Different factors influencing adherence as identified by different authors were discussed. Most factors are not conclusively associated with adherence to antiretroviral therapy and can therefore not be used to predict probable adherence. Factors that are conclusively associated with inadequate adherence should caution the healthcare provider to intensify adherence support.

A patient's readiness to commence antiretroviral therapy should be assessed prior to the onset thereof. All factors that may interfere with optimum adherence should also be stabilized.

The various methods to determine adherence were explained in terms of their sensitivity and correlation with virus suppression. No single method is accurate enough in isolation to determine actual adherence. Authors suggest that a combination of methods be used to enhance accuracy of adherence evaluation.



CHAPTER 2

RESEARCH METHODOLOGY, THE RESEARCH SITE AND BIOGRAPHICAL DATA OF THE PARTICIPANTS

2.1 INTRODUCTION

A qualitative descriptive and exploratory research approach was used to conduct this study. Qualitative research is a systematic, interactive and subjective method to describe lived experiences. This method enables the researcher to give meaning to experiences which have an influence on adherence to antiretroviral therapy. In turn the researcher and the reader are able to better understand the difficulties associated with adherence to long term-treatment. As emotions linked to lived experiences are difficult to measure, qualitative research provides an effective means to investigate these responses (Burns & Grove, 2001:26-27; Yin, 2003:2).

2.2 THE RESEARCH DESIGN

The goal of the study is to enhance the understanding of inadequate and adequate adherence as phenomena. An extensive description of participants' experiences regarding adherence to antiretroviral therapy by exploring their histories and previous behaviour patterns in detail, may shed new light on this problem. For this reason a **descriptive** and **exploratory case study** design was selected to conduct the research.

A **descriptive** approach enables the researcher to organize data in such a way that it becomes meaningful and induces insight (Burns & Grove, 2001:3, 4, 52, 248).

The **exploratory** approach was designed to help the researcher to detect unexpected events and to prevent failure to notice crucial patterns. After detecting possible patterns, the researcher can identify and consequently describe these patterns. The researcher's mindset should be flexible, open to the unexpected and sensitive to patterns. By using this approach a new depth of meaning can be achieved (Burns & Grove, 1997:437; Burns & Grove, 2001:374; Yin, 2003:30).

Yin (2003:30) provides specific criteria to which an **exploratory** approach should conform. These criteria recommend what data to collect and how to analyze it.

The criteria according to Yin are:

1. Aspects to be explored

The purpose of this study is to explore the factors associated with adherence to antiretroviral therapy for the treatment of HIV infected women attending an urban private healthcare facility.

2. The purpose of the exploration

The purpose of the exploration is to provide information and better insight into **how** HIV infected women from an urban private healthcare facility manage to adhere to their antiretroviral therapy, as well as **why** it is sometimes difficult to do so.

3. The criteria by which the exploration will be judged as being successful

The exploration will be deemed successful when data saturation occurred. Furthermore, the data collected during the data collection phase should answer the research question (Ibid, 30).

'...case studies are the preferred strategy when "how" or "why" questions are being posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real-life context' (Yin, 2003:1, 7-8).

Case study research enables the researcher to explore a unit, in this case participant behaviour, extensively while maintaining the holistic characteristics of real-life events.

These may include individual life cycles and organizational processes. It also provides great detail regarding context, innovation and creativity of a participant in a specific situation. Although the number of participants in case study research may be small, the number of variables is large. It is, however, important to examine all variables involved or those that may cause an impact on the adherence of the participant (Burns & Grove, 2001:255; Yin, 2003:2, 8, 85-92).

2.2.1 Data collection strategies

Documents, archival records, interviews, direct observation, participant observation and physical artifacts can be used to provide additional detail (Burns & Grove, 2001:255; Yin, 2003:2, 8, 85-92).

2.2.1.1 Documents

The medical records used in this case study provided additional data and were used to confirm and supplement information from interviews with the participants and personnel. Laboratory results provided each participant's immunological and clinical history. Additional clinical data were derived from records such as radiology reports. Each patient's treatment history was compiled from the prescription copies in the medical records. This information gave clues to possible difficulty with adherence. For example, an increase in viral load after adequate virus suppression was suspicious of inadequate adherence. The specific participant was then questioned on her adherence during that specific time.

A fine example would be Participant 10. The participant displayed complete virus suppression for several years on the same treatment regimen and then suddenly records showed virus rebound. When questioned about this incident, the participant explained that because of a high CD4 cell count the doctor recommended that

treatment be interrupted for a while. The treatment was discontinued for three months but had to be re-commence due to an increase in viral load and a decrease in CD4 cell count from 778 cell/uL to 317 cells/uL (*See Appendix I Figure 2.14*).

While some participants were on antiretroviral therapy for several years (P2, P4, P6, P7, P10, P11, P12), others commenced treatment only recently (P1, P3, P5, P9) (*See Appendix I*).

Virus suppression while on antiretroviral therapy was complete and sustained for two participants (P4 and P12), while two more participants displayed complete virus suppression with only one incident of virus rebound each (P2 and P10). Probable reasons for virus rebound in Participant 2 were unknown, but Participant 10 temporarily interrupted treatment on recommendation of the doctor (Structured Treatment Interruption) (*See Appendix I; Figures 2.7, 2.9, 2.14, 2.16*).

Of the remaining participants, five displayed incomplete virus suppression. The CD4 cell count of two of these participants were unstable (P1 and P11), one participant (P9) displayed a decline in CD4 cell count and the other two showed a slight but steady increase (P3 and P7) (*See Appendix I; Figures 2.6, 2.8, 2.12, 2.13, 2.15*).

The two remaining participants displayed interesting responses to treatment. Participant 5 showed an initial increase in viral load before it declined sharply with consequent sustained incomplete virus suppression. This participant's CD4 cell count however started to increase slightly since commencing treatment (*See Appendix I; Figure 2.10*).

Participant 6 reported that severe nausea was experienced with the first antiretroviral regimen and eventually asked the doctor to change it. However, during this period this participant continued to take the medication as prescribed, in spite of the side-effects. The viral load indicated poor suppression and the CD4 cell count remained

low. After the regimen had been changed, the CD4 cell count rose dramatically while the viral load became undetectable (*See Appendix I; Figure 2.11*).

Documentary information that contradicts data derived from other sources must be clarified by further investigation (Yin, 2003: 87). This discrepancy had not been found in this study.

During the interview one participant mentioned that the discovery of being HIV positive had been made when diagnosed with tuberculosis meningitis. This information had been confirmed from a referral letter and a sick note on the participant's file.

2.2.1.2 Interviews and direct observation

Four to five consecutive individual interviews over a period of at least six months were conducted with each participant. Participants were observed for non-verbal communication that could unlock further detail regarding the issue under discussion. These observations were noted in the verbatim transcripts.

Interviews were also conducted with the doctor and the professional nurse who was responsible for services provided at the specific private healthcare facility. This information was used to complete the scenario sketched by the medical records and the participant interviews. They were asked to provide information regarding the following:

1. Preparation of patients for treatment

Patients were mostly prepared for antiretroviral therapy during their consultation with the doctor, or when referred to the professional nurse following their consultation with the doctor.

The main topics discussed during such a session were:

- The correct way of taking the medication
- Rationale for adequate adherence and what adequate adherence involves
- The consequences of inadequate adherence

Psychological readiness was particularly stressed by the professional nurse who explained to patients that they should rather postpone treatment if they feel that they cannot cope with it (*See Appendix H*).

2. Perceived level of adherence of patients attending the private health care facility

The average level of adherence was considered to be good, as patients achieved virus suppression on the same antiretroviral regimen for five to seven years. There were, however, exceptions where adherence was known to be poor (*See Appendix H*).

3. The general attitude of patients towards antiretroviral therapy

Most patients were positive, even when they experienced side-effects and understood what the treatment entails. Most patients were contacted or contact were made regularly by them, which allowed them to discuss and clarify treatment-related problems and emotions (*See Appendix H*).

4. Possible reasons for inadequate adherence

The doctor considered psychological stress, either personal or induced by external factors, to be an important reason for inadequate adherence. The professional nurse perceived that difficulty obtaining medication, financial limitations and side-effects also impacted negatively on adherence. Language proved to be

problematic in an estimated 10% of participants. This problem was overcome by the use of a translator and interpreter (*See Appendix H*).

5. Intervention and support provided by the private health care facility to facilitate adherence

Patients, who experienced difficulty in accepting their diagnosis and the need for treatment, were referred to a qualified professional for psychological help.

Care had been taken to build a relationship with each patient. Patients were treated as friends and equals. Each patient who commenced treatment was provided with the professional nurse's cellular phone number who was thus available for treatment and emotional support most of the time (*See Appendix H*).

6. Measures to ensure continuity of support

Medication could be collected throughout the year, except for holidays and weekends, as the receptionist was always on duty, even though the doctor was not available.

All HIV positive patients received the doctor's cellular phone number during the first consultation and could contact him at any time.

Patient files were used to document activities like progress with regards to HIV Management Program registration and communication with the medical aid.

When on leave the professional nurse was usually relieved by a locum. This person had been briefed on issues in progress regarding patients' treatment (*See Appendix H*).

7. Procedures followed when a patient is suspected of being inadequately adherent

These patients were usually referred for psychological help. Both the doctor and the professional nurse usually gave special attention to these patients and re-discussed issues concerning antiretroviral therapy. Patients, who persisted with inadequate adherence, were eventually recommended to discontinue treatment (*See Appendix H*).

2.2.1.3 Participant observation

The context of this study did not allow for direct observation of participants, except during an interview, as it would be an intrusion on their privacy and could possibly compromise their confidentiality. The researcher could for example, not physically observe a participant's adherence behaviour as it would entail that she should be present at the participant's home and/or workplace in order to do so. On the one hand the researcher's presence might have been suspicious towards other people thus compromising the participant's confidentiality. On the other hand it could also induce adherence on the part of the participant that may not have been the case if the researcher was not present (Burns & Grove, 2001:41).

Due to the stigma of HIV, patients and thus also participants, are isolated. Very few of them were prepared to take part in a support group. The researcher could therefore not take part in adherence-related activities for observational purposes.

The researcher was also not allowed to sit in during participant consultations with the doctor as this intervention may have curbed the participant's responses regarding adherence. The researcher would also have intruded on the participant's privacy, especially when other health matters were discussed.

The researcher undertook that neither the participants' identity nor any other

information that they revealed, be discussed with their doctor. This was an important agreement as it allowed participants to be more honest and open about their experiences regarding adherence. Some of these experiences also included their relationship with their doctor and other healthcare service providers. If they were not protected against exposure, they may withhold important information in fear of discrimination.

2.2.2 Statements that guided the execution of the research design

This *exploratory descriptive case study* was guided by the following statements as described by Yin (2003; 2, 8):

- Little data regarding adherence to antiretroviral therapy for the treatment of HIV infection among women in the South African context was available, as justified in the literature review.
- The aim of this research was to determine factors and probable patterns associated with adherence, not the prevalence thereof (Ibid, 2, 8). Prevalence of these factors was not relevant to this research question for the reason that if a specific factor influences the adherence of one person, it may also influence the adherence of others. All possible factors should be taken into consideration when building a culturally appropriate strategy to improve adherence for each individual.
- Information was collected until data saturation in this population occurred (Ibid, 2, 48). The research population was exhausted after eleven participants were selected (*See Figure 2.1; Table 2.2*). However, if data saturation had not been achieved after completion of data collection from these eleven participants, the researcher would have contacted all patients who

commenced therapy since selection of the current eleven participants. Data would then be collected from the newly added participants. This process would have been repeated until data saturation in the greater population occurred. This was, however, not necessary as data saturation had been achieved in the initial selected sample.

Factors that are associated with adherence to antiretroviral therapy could be such a phenomenon that has to be studied in a real-life context.

2.3 THE RESEARCH PROCESS

2.3.1 The research site

Information had been derived from interviews with the doctor and professional nurse at the health care facility, as well as the researcher's direct observations.

For the purposes of this study a single site had been selected. Participants attended a private healthcare facility in an urban setting. The healthcare facility provided general medical care, but more specifically medical care regarding infectious diseases. All patients attending the facility were not HIV positive.

Health care was provided to patients, including the participants, by a physician specialized in infectious diseases and a professional nurse experienced in the care of HIV patients. No standard adherence program was compulsory to patients before and/or during treatment.

2.3.1.1 Personnel

The professional nurse

The professional nurse was involved in the emotional and medical care of most of the patients attending the facility. On initiation of therapy most patients attended an information session with the professional nurse. Side effects of the prescribed antiretroviral drugs, the importance of adherence and virus resistance against antiretroviral drugs were the topics mostly discussed with patients. Discussions were tailored around the patient's needs. However, of the 11 participants in the study, the professional nurse prepared only two for antiretroviral therapy, namely P9 and P10 (See Table 2.1; Appendix H).

The professional nurse did not have a discussion with some of the patients prior to initiating antiretroviral therapy, as the attending doctor sometimes consulted patients outside office hours. This was relevant for four of the research participants, specifically P3, P5, P11 and P12. The doctor informed these patients of the aspects of treatment. This category usually comprised patients from overseas and other African countries (See Table 2.1).

Some patients commenced therapy at another doctor and therefore allegedly needed no preparation for therapy. They only consulted the professional nurse when seeking help or information. No records were kept of the details of these discussions. Three participants in the study commenced treatment at another doctor. They were P1, P4 and P7 (See Table 2.1).

One participant, P2, reported that except for guidelines regarding how to take her antiretroviral drugs, no additional information regarding the importance of adherence or the development of resistance had been received (See Table 2.1).

All patients had personal and telephonic access to the professional nurse for inquiries and support during office hours. According to two participants, she assisted them

emotionally or with information (See Table 2.1).

Patients did not have to make an appointment to be able to see the professional nurse. If she was engaged elsewhere they had to wait. The nurse's cellular phone number was made available to some patients for use in an emergency, in particular those who started on antiretroviral therapy recently.

Since initiation of the study, the professional nurse resigned and was not replaced. During her employment this nurse was involved in the care of the following participants:

Table 2.1 Involvement of the professional nurse in the care and orientation of participants

Participant	Preparation for antiretroviral therapy	Patient follow-up
P 1	Commenced antiretroviral therapy at another doctor who prepared participant for treatment	Professional nurse supplied information sought by the participant once
P 2	None	Asked doctor once about side-effects
	Doctor prepared participant for treatment	None
P 4	Commenced antiretroviral therapy at another doctor who prepared participant for treatment	None
P 5	Doctor prepared participant for treatment	Doctor from medical aid
P 6	None	Asked the doctor for information when it was needed
P 7	Commenced antiretroviral therapy at another doctor who prepared participant for treatment	None
P 9	Professional nurse prepared participant for the prevention of mother-to-child transmission protocol	None
P 10	Professional nurse prepared participant for treatment	Professional nurse supplied continued support and information
P 11	Doctor prepared participant for treatment	Asked the doctor for information when it was needed
P 12	Doctor prepared participant for treatment	Asked the doctor for information when it was needed



The doctor

All patients had access to the doctor during office hours for telephonic or personal consultation. Personal consultations took place according to appointment. All HIV positive patients received his cellular phone number in case of need. During periods of absence patients could contact the doctor on his cellular phone.

Before initiation of therapy the doctor had a discussion with each patient, explaining the need and requirements for antiretroviral therapy. Consequences of inadequate adherence were also discussed. The doctor did not keep notes on the content of information discussed with patients.

The receptionist

The receptionist is mainly responsible for phoning or sending a SMS message to patients when their medication arrives at the healthcare facility. Delivery and collection of medication was recorded in a register. The receptionist is aware of which patients in the facility are HIV positive, but signed a confidentiality and non-disclosure agreement on employment. The receptionist is also responsible for preparing files for consultations and has to ensure that the blood results are available when the patients arrive.

The filing clerk

All laboratory results reach the facility in an envelope delivered by hand by the laboratory clerk. This method ensures confidentiality. The filing clerk is responsible for filing blood results and is therefore aware of which patients attending the facility are HIV positive. As the private healthcare facility also provided a service to patients with general medical problems, not all patients attending the facility were HIV positive.

The filing clerk sometimes assists the doctor, professional nurse and receptionist in

communicating to patients where language proved to be a problem.

2.3.1.2 Consultations

First consultations

All newly HIV diagnosed patients (including referrals), underwent a full physical examination and blood tests. A chest X-ray was taken to exclude possible underlying pathology. The CD4 cell count and viral load guided the decision for treatment initiation.

If the patient was to commence treatment, the additional laboratory and radiology data were used to determine which treatment would be most suitable. The facility used the Johns Hopkins and South African HIV Clinicians Society's guidelines regarding preparation and commencement of therapy (Bartlett, 2005:8; SAHIVCS, 2002:6-9).

Follow-up consultations

Patients were required to make an appointment to see the doctor. Depending on the workload of the facility, the availability of appointments varied. Consultation times were from 10:00 in the morning until 16:00 in the afternoon. Consultation appointments were not available over weekends. Patients who were admitted to the hospital were seen once or twice per day or when necessary.

Follow-up blood tests need to be done at least two days prior to their scheduled appointment with the doctor. This allows time for results to reach the facility in time. Patients usually receive the laboratory request form for the next follow-up blood tests at their previous consultation with the doctor. When patients lost their laboratory request form, they usually phoned the facility and the professional nurse or doctor prepared a duplicate laboratory request form. It was then either faxed through to them, or they could collect it. A few patients came for their follow-up consultation

without first having completed the blood tests. They were then requested to come back in at least two day's time so that the doctor could discuss their results with them. It is the policy of the facility not to discuss a patient's results telephonically. Personal consultations better allows for discussion of implications and further action. These consultations also give patients the opportunity to ask questions.

Emergency consultations

Patients presenting with a medical emergency are usually accommodated. When unavailable, patients have the option to contact the doctor on the relevant cellular telephone number. Problems that can not be solved telephonically are referred to another doctor or the emergency facility on the same premises.

2.3.1.3 Medication

Patients have several options in obtaining their medication. Some prefer to receive a prescription from the doctor which they then hand in at a pharmacy of their choice. They have to collect their medication every month.

Most patients, also patients from elsewhere in Africa, choose to register at a medication distribution company, who then delivers their medication monthly at a destination of the patient's choice. Many of these patients prefer that their medication be delivered at the medical facility as they felt it protected their confidentiality. All delivered medication is identified only by the patient's details. No mention is made of the content of the parcel.

A few patients from elsewhere in Africa, for whom it is difficult to collect medication monthly in South Africa, and to whom the services of a medication distribution company is not available, buy several month's medication in bulk. They usually prefer not to obtain the medication in their own countries for reasons of confidentiality,

medication availability and prices.

Measuring adherence

Medication collection from the facility (applicable only to patients whose medication is delivered at the facility) self-report, pill counts, adherence as perceived by the health care provider and viral load suppression, were methods used at the facility to monitor adherence.

Patients who commenced treatment were requested to bring along their medication containers for the first few follow-up visits. The professional nurse then performed a pill count. Viral load rebound after suppression in the absence of an acute infection, or an inability to reach undetectable viral load from six months on therapy, were considered to be suspicious of inadequate adherence.

Patients on treatment were scheduled for follow-up visits and laboratory tests (efficacy and toxicity monitoring) every three to six months, depending on their stage of treatment, financial and geographical situation. Follow-up visits and laboratory testing were considered to be part of adherence. The information derived from the blood tests and physical examination guided the doctor's decision regarding the patient's antiretroviral therapy.

Patients who did not return for their follow-up toxicity and efficacy monitoring were contacted telephonically and reminded of the blood tests and that they should secure an appointment with the doctor within two days.

Patients who did not adhere were submitted to an in depth adherence discussion with the doctor and the professional nurse and sometimes referred to a professional counselor, psychiatrist or psychologist for counseling and/or therapy. Issues of inadequate adherence were again discussed. The danger of developing resistance

and culturing a resistant population were also discussed. Patients who repeatedly failed to adhere to their treatment program were explained to that their treatment would be discontinued due to the danger of continuing treatment without adequate monitoring. If the patient still did not adhere, the treatment was stopped altogether. Discontinuation of treatment was considered as a last resort and seldom imposed. Patients were, however, ensured that whenever they feel ready they could return and treatment will be re-commenced (*See Appendix H*).

2.3.2 The research population

Since February 1998 up to the time that the research was commenced, 332 HIV positive patients attended the facility (*See Table 2.2*). Most patients were from surrounding areas, but patients from outside South African borders and other parts of the country also attended. Patients were mostly referred to the facility by general practitioners and other specialists. Occasionally a patient would attend the facility without any formal referral. These patients usually heard about the facility from a friend or family member.

Table 2.2 Breakdown of patients enrolled at the facility during the period 1998 until September 2004

Year	Number of Patients
1998	1
1999	31
2000	49
2001	75
2002	63
2003	72
2004 until September 2004	51
Total	332

The literacy and educational level as well as occupational distribution among the patients were wide-ranging.

All patients paid for services rendered by the private healthcare facility. Most funding derived from medical aids but some patients had to pay for services and medication from their personal funds. Some of the patients covered by medical aid still had to contribute to be able to afford medication as some medical aids' budgets for antiretroviral therapy are limited to laboratory testing and follow-up visits to the doctor.

Medical aid cover for HIV constantly evolves and some patients, who previously could not afford antiretroviral therapy through their medical aids, are now able to do so. This may also be contributed to the sporadic decrease in the prices of antiretroviral drugs.

The social status among patients attending the facility varied greatly. Most patients were earning an income. Patients not earning an income were mostly dependent on someone earning an income and could therefore pay for medical services.

2.3.3 The research sample

2.3.3.1 The sampling process

In September 2004, a list of all HIV positive patients who attended the healthcare facility during that year was prepared. Patients who did not attend the facility during the previous nine months, were considered to be no longer on therapy as their prescription would have expired. Patient follow-up at the doctor is scheduled for every three to six months and patients who did not attend the facility during the previous nine months were considered to be no longer under treatment at this facility.

Of the 332 adult patients who visited the facility 163 were female. The group of females included 129 black women. The black female patients who did not visit the

facility during the previous nine months numbered 65. Of the remaining 64 black female patients, 20 were not on treatment. Another eight patients came from other parts of the country or from outside South Africa (See Figure 2.1).

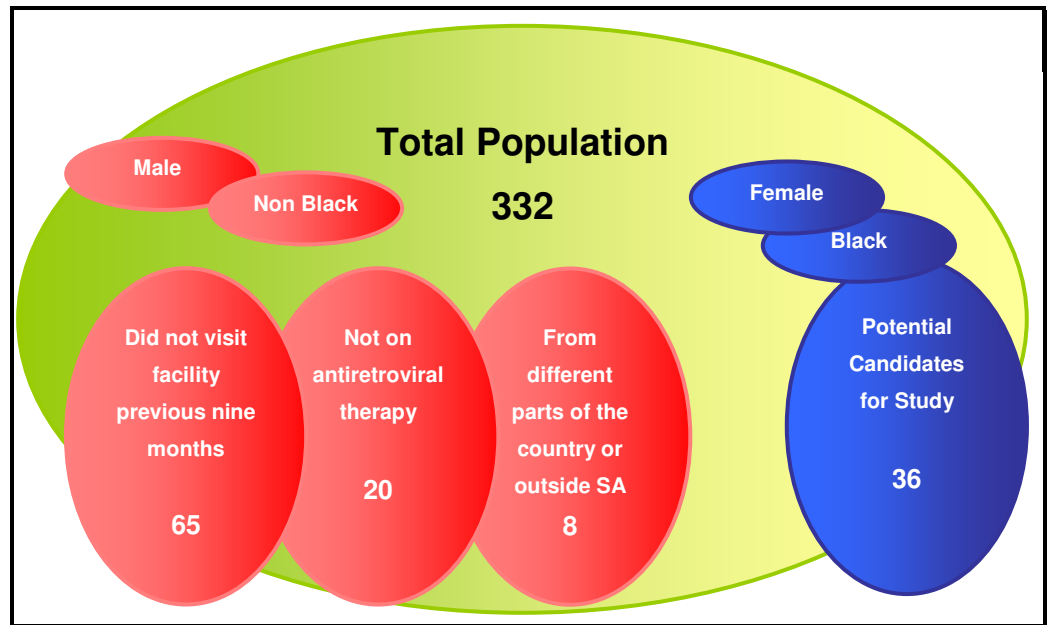


Figure 2.1 Diagram of exclusion illustrating how the group of potential candidates was selected

The remaining 36 candidates were randomly selected according to the Table of Random Numbers (Burns & Grove, 2001:760). The first 14 candidates on the list were contacted telephonically and notified of the research project. The following points were discussed with each prospective candidate:

1. The purpose of the research is to help people who are struggling with antiretroviral therapy as well as preparing people who are going onto treatment for the first time.
2. The aim is to equip healthcare workers with a better understanding of the difficulties experienced by people regarding adherence to antiretroviral therapy. This knowledge and understanding can then enable them to better support people on antiretroviral therapy.
3. The research project is confidential and no information will be passed on to the doctor without the participant's explicit consent.



4. Interviews will run for 30 to 45 minutes per session with a maximum of six sessions distributed over six months.
5. For privacy and confidentiality purposes, it will be best to conduct the interviews at the healthcare facility. (Two participants requested that the interviews were to be conducted at their respective offices. It was agreed to as firstly, the participants were comfortable with the arrangement, and secondly, they were able to provide private facilities).
6. Interviews will be audio-recorded for reference purposes. (Technical failure caused two complete and one partial interview not to be audio-recorded. The researcher documented notes during these interviews. The last interview was conducted according to a questionnaire and the participants' answers were documented during the interview).
7. A summary of the previous interview will be presented to the participant for clarification and confirmation at the next session.
8. Data from all participants will be summarized in a research report and will be published.
9. If a patient prefers not to participate she will not be discriminated against.
10. Any participant can stop participation in the research at any time during the research. No reason needs to be supplied, but a discussion regarding this participant's decision with the researcher will be appreciated.
11. No participant will receive any direct benefit, for instance financial grant for her participation in the study. However, if it is financially difficult to attend the sessions, she can request financial help from the researcher.
12. In the event of a participant developing a need for counseling or psychological support, the researcher will refer her for specialized help. [This was not necessary in the course of this study.]

Most candidates were eager to participate in order to help others in need. There were, however, several factors preventing candidates from becoming participants in the research project.



1. Time constraints imposed by working hours or work responsibilities, not being able to attend interviews during weekends or after hours and driving time, or transport problems especially after hours and over weekends prevented seven candidates from participating.
2. Two candidates indicated that they were not interested to participate in the research project.
3. Four candidates were not available at the contact number(s) indicated on their medical files or on their accounts and another two had incorrect contact number(s) on their medical and account files.
4. Five candidates agreed to participate and made appointments but did not turn up. All these candidates were contacted again. Three of them were no longer available at their contact numbers. One participant still indicated that participation was likely, but will come back with an appointment time. In failing to do so, contact was again made and the same answer had been supplied. The name of this person was then removed from the list as a potential participant in this study. The other participant made a second appointment and also did not turn up. This potential participant was not available afterwards. This person's name was also removed from the list as a potential participant in this study.

In spite of them indicating that they were interested in participating in the study, all five of the above mentioned candidates' names were removed from the list for the following reasons:

1. In repeatedly failing to secure a first appointment, they would have been unlikely to complete the interviews required by the study.
2. They may have felt that in refusing to participate in the study they will be victimized or penalized and therefore pretended to be willing, although they did not really feel to participate.
3. They may have been displaying the Hawthorne effect by supplying the answer that they imagined the researcher would like to hear, but then found excuses not to participate (Burns & Grove, 2001:41; Gross *et al.* 2001:2117).

One candidate has been removed from the list because of a psychiatric background. The researcher is not trained in psychotherapy and felt that an interview regarding adherence may compromise the candidate's current psychiatric therapy.

Another candidate has been removed from the list due to business relations with the researcher.

Two candidates were too ill to travel and even conducted a telephonic interview. They would probably not have been able to complete the interview series and were therefore excluded from the list (*See Table 2.3*).

Table 2.3 Reasons for exclusion as participants from the study

Reason for exclusion as participant from study	Number of patients
Too busy to take time off from work Not able to attend sessions over week-ends or after hours Transport problems after hours and on week-ends	7
Did not want to participate	2
Not available at the contact numbers on their files The contact numbers on the file and accounting system were incorrect	6
Agreed to participate but did not turn up for appointment.	6
Psychiatric problems	1
Business associate	1
Too ill to travel or to conduct conversation over the phone	2
Total number of candidates	11

The initial aim of the study was to start with fourteen participants to allow for participants wishing to leave the study. It was, however, not possible to select fourteen participants as population exhaustion was encountered after eleven participants were selected.

The intention of the study was to follow and record the experiences of eight participants for at least six months. Initiating the study with eleven participants will allow for patients who do not complete all the interviews. The interview period ran

throughout December for seven of the candidates, and throughout the Easter holidays for eight of the candidates. Including these significant holidays in the study allowed for collection of data related to the impact of holidays and change in daily routine on adherence.

2.3.3.2 Sample characteristics

Only black adult women were included as some research literature indicated that age, gender and race have an influence on adherence (Tsasis, 2001:110; Mellins *et al.* 2003:408; Laine *et al.* 2000:171; Turner, 2002:S148; Kemppainen *et al.* 2001:123-125; Silveira, Draschler, Leite, Pinheiro & da Silveira, 2002:167; Singh & Squier, 1996:[5]).

All participants were able to communicate in either English or Afrikaans. The researcher is not fluent in other languages and the use of a translator might have compromised confidentiality. Using another interviewer fluent in other languages may have contaminated or limited data collection, as the researcher would have no power over what had been discussed.

At the time of sampling all the participants were on antiretroviral therapy as the researcher aimed to collect data with regard to adherence in a real life context. The period of treatment amongst the participants varied between several months to several years. One participant was pregnant and on antiretroviral therapy for prophylactic reasons at the time that the research was commenced. Treatment will be discontinued as soon as the baby is born, due to the current immune status not warranting antiretroviral therapy. Another participant fell pregnant during the data collection phase. This participant was on treatment due to the compromised immune status, and would therefore continue after birth of the child.

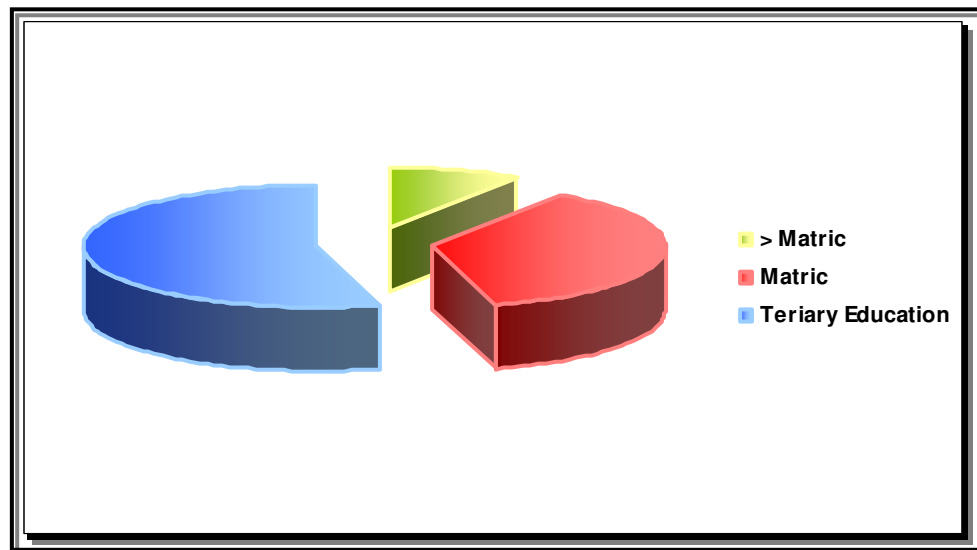


Figure 2.2 Educational distribution of participants

In the research population, four participants have concluded their school education while one has left school before completion. The other six participants achieved different levels of tertiary education and at least two of them were busy with further studies (See Figure 2.2; Table 2.4).

Only one participant fell in the age group 18 to 29 years, while most of the participants were in the age group 30 to 39 years. Two participants were in the age group 40 to 49 years. One of the participants was originally from another African country, but resided in South Africa for longer than 10 years. This person was included in the study as antiretroviral therapy is not limited to citizens of South Africa only. Of the eleven participants, five were not married, of which two were in long-term relationships at the time of the research, five were married and one divorced (See Table 2.4).

All the participants were working and financially independent to some extent. Different medical aids provided 100% cover for five of the participants, four of them received partial cover from either their medical aid or a company benefit, and had to contribute to be able to sustain antiretroviral therapy. Another two persons paid for their

treatment out of their own personal funds. Both were not registered at their respective medical aids for HIV benefit. One participant who believed it would be too much of a bother due to previous trouble with the medical aid for not paying medical bills, would rather be in control of the situation and use own funds. Another participant was not aware of the fact that one has to register for HIV benefit. Since the study commenced this person registered with a medical aid, and only needed to contribute a co-payment (See Figure 2.3; Table 2.4).

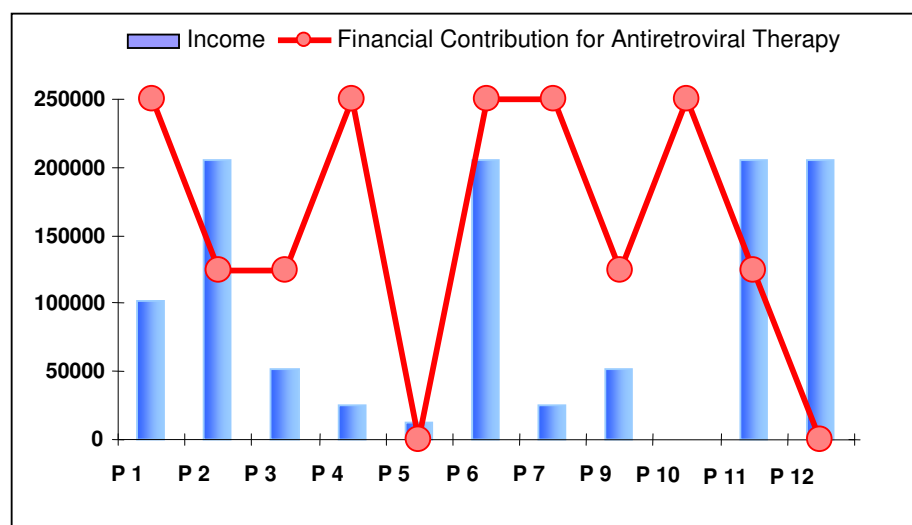


Figure 2.3 Income distribution vs. financial contribution for antiretroviral therapy of participants

Perceived social support was evaluated according to the MOS Social Support Survey instrument (Rand Health, 2004). The interpretation of this instrument is a relative value where 100 indicates maximum and 0 indicates minimum support. The lowest score indicated by a participant was 69.4. According to these results social support was perceived as moderate to very good (See Figure 2.4; Table 2.4).

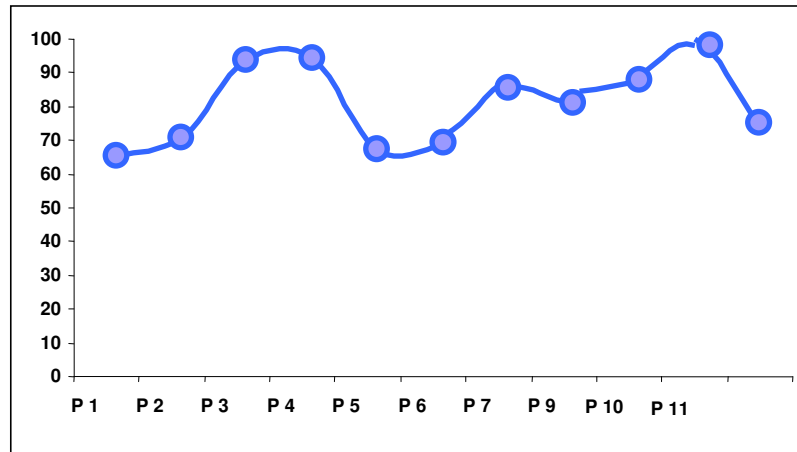


Figure 2.4 Perceived social support as reported by participants

Table 2.4 A summary of participants' demographic information and perceived social support as measured by the MOS Social Support Survey

Study ID	Age group	Marital status	Racial group	Income p.a.	Job description	Highest level of education	Means of payment for medication and health care	MOS
P 1	30-39	Married, no extramarital sexual relationship	Xhosa	R102 401 – R204 800	System Administrator	Matric	Medical Aid 100%	69.4
P 2	30-39	Unmarried, living alone, sexual relationship	Xhosa	> R204 801	HR Specialist	Tertiary education	Medical Aid with co-payment	75
P 3	18-29	Unmarried, living alone, sexual relationship	Sotho	R51 201 – R102 400	Traffic Officer	Matric	Medical Aid with co-payment	97.9
P 4	30-39	Married, no extramarital sexual relationship	Zulu	R25 601 – R51 200	Training	Tertiary education	Medical Aid 100%	98.6
P 5	30-39	Married, no extramarital sexual relationship	Tswana	R12 801 – R25 600	Tea lady	< Matric	Own funding	71.5
P 6	30-39	Married, no extramarital sexual relationship	Tswana	> R204 801	Prosecutor	Tertiary education	Medical Aid 100%	73.6
P 7	30-39	Unmarried,	Zulu	R25 601 –	N/a	Tertiary	Medical Aid	89.6



		living alone, sexual relationship		R51 200		education	100%	
P 9	30-39	Divorced/separated, living alone, no sexual relationship	Ndebele	R51 201 – R102 400	N/a	Matric	Medical Aid with co-payment	85.4
P 10	40-49	Unmarried, living alone, no sexual relationship	Sotho	R51 201 – R102 400	Public Relations	Matric	Medical Aid 100%	89.7
P 11	30-39	Unmarried, living with someone, no sexual relationship	Zulu	> R204 801	N/a	Tertiary education	Company Benefit with co-payment	100
P 12	40-49	Married, no extramarital sexual relationship	Foreigner	> R204 801	Lawyer	Tertiary education	Own Funding	74.3

2.3.3.3 Background and impressions of each participant

Participant 1

The first participant was recruited in October 2004. She seemed very eager to participate in the research project. She once stated that it is almost like counseling and that it helps a lot. Her baby girl's presence during the first interview was somewhat disruptive, but also allowed an opportunity for the researcher and participant to become comfortable with each other. After the third interview the participant seemed to become a little distant. When probed about the observation she explained that she was very busy. Securing appointments for the fourth and fifth interviews were problematic. She experienced trouble with transport and did not turn up for two appointments. The researcher experienced difficulty contacting her, but eventually managed to establish telephonic contact during May 2005 (*See Table 2.5*). Even during the final (fifth) interview the participant was not as open and responsive as during the first three interviews, as if something was troubling her. The researcher did not probe further into the matter because the participant's response to the previous enquiry, whether something was amiss, did not bear any fruit.

The participant initiated antiretroviral therapy in 1997 with zidovudine, lamivudine and stavudine. Therapy was discontinued at the end of 2000 on advice of her physician. Shortly after her treatment was stopped, the doctor vanished and she remained without treatment until the beginning of 2004. The participant then recommenced treatment with zidovudine, lamivudine and nevirapine at her current specialist.

Table 2.5 Field diary indicating contact with Participant 1

P 1	18-10-2004	Participant contacted and agreed to participate in study. First appointment set for 25-10-2004
	25-10-2004	Participant's baby was present at interview and interfered with conversation. Valuable information was still collected.
	15-11-2004	Second interview conducted
	13-12-2004	Third interview conducted
	17-01-2005	Appointment for fourth interview: Participant did not turn up. On follow-up call she explained that she had an emergency at home
	24-01-2005	Appointment for fourth interview. During call to confirm appointment, participant requested that appointment be moved to 31-01-2005
	31-01-2005	Fourth interview conducted
	14-03-2005	Appointment for fifth interview: During call to confirm appointment, participant requested that appointment be moved to 15-03-2005 due to a transport problem
	15-03-2005	Appointment for fifth interview: Participant did not turn up. No explanation was given at follow-up call
	04-04-2005	Appointment for fifth interview: Participant did not turn up
	25-04-2005	Participant agreed again to continue with interviews from the middle of May
	06-06-2005	Fifth interview conducted. Participant informed regarding termination of interviews during this session. Researcher will contact participant for final review of research report at the end of September 2005

Participant 2

The participant agreed to take part in the research project, but was reserved from the beginning. During the recruitment telephonic conversation, she voiced her concern that she cannot contribute much. She could not be reached for further interviews following the first one and has consequently been removed from the participant list (See Table 2.6).

Participant 2 commenced treatment in 2002 with zidovudine, lamivudine and efavirenz and was still on the same regime when the study commenced.

Table 2.6 Field diary indicating contact with Participant 2

P 2	01-11-2004	Participant contacted and agreed to participate in study. First appointment set for 04-11-2004.
	04-11-2004	First interview conducted. Participant indicated that she could not see her involvement in the research and will possibly not complete all the interviews.
	December 2004	Participant not available on contact number
	January 2005	Participant not available on contact number. Participant consequently removed from participant list

Participant 3

The third participant was willing to take part in the research project, but it was difficult to secure the first appointment. She had difficulty in organizing transport to attend the first appointment. The researcher cancelled the fourth appointment due to a personal emergency. The participant was notified on the morning of the appointment. The fourth appointment was not attended by the participant. No explanation was provided when probed about the incident. The researcher left it there to avoid being patronizing and give the participant the impression that she is being observed (*See Table 2.7*).

The participant commenced with antiretroviral therapy in April 2004 with zidovudine, lamivudine and efavirenz. The participant was ill at the time. Since the beginning of the interviews she fell pregnant and the efavirenz was stopped due to its known teratogenic effects. The baby was due in July 2005. Until the birth of the baby she would use only zidovudine and lamivudine.



Table 2.7 Field diary indicating contact with Participant 3

P 3	18-10-2004	Participant contacted and agreed to participate in study. First appointment set for 25-10-2004
	25-10-2004	Appointment for first interview moved to 26-10-2004
	26-10-2004	Participant did not turn up. During follow-up call to reschedule appointment she explained that she had transport problems. A new appointment was set for 02-11-2004
	02-11-2004	First interview conducted
	02-12-2004	Second interview conducted
	10-01-2005	Phoned participant to set up appointment for third interview. Called again next week for third appointment
	27-01-2005	Third interview conducted
	01-03-2005	Appointment for fourth interview. Cancelled by researcher due to emergency
	15-03-2005	Appointment for fourth interview. Participant did not turn up. During the follow-up call to reschedule appointment no explanation was given. Appointment was rescheduled for 07-04-2005
	07-04-2005	Fourth interview conducted
	23-06-2005	Fifth interview conducted. Participant informed regarding conclusion of interviews during this session. Researcher will contact participant for final review of research report at the end of September 2005.

Participant 4

Participant 4 was skeptic about the nature of the research and requested to see the researcher at the medical facility for a discussion, before deciding to take part or not. Two and a half weeks after the first interview, the participant contacted the researcher and asked to do the second interview. She made an appointment to see the doctor, as she was suffering from a severe rash. Although this was shortly after the first interview, the researcher felt that the participant's experiences whilst having this severe rash could be valuable in capturing the influence of side-effects on adherence. Some of these impressions may be lost if she was only asked to voice it later on. The specific interview was therefore shorter than anticipated as she was feeling ill, and the line of conversation was more focused on side-effects and her experience thereof. After the third interview, it became difficult to secure an appointment with her. Her father suffered a stroke and she was occupied with his homecare. The last interview was conducted when she was in the vicinity of the medical facility. For reasons of

time and transport restrictions, the fourth and fifth interviews were combined (See *Table 2.8*).

The participant initiated antiretroviral therapy in 1998 with stavudine, didanosine and hydroxyurea. She then changed to zidovudine, lamivudine and efavirenz in 2003 due to ineffectiveness of the current regimen (possible resistance). She developed a rash from the efavirenz and requested the doctor that it should be changed. She then commenced with zidovudine, lamivudine and nevirapine. She also developed a rash due to the nevirapine and discontinued treatment for two months on advice of her general practitioner (GP). Her HIV specialist was away on conferences and leave at the time. On follow-up, he advised her to re-commence therapy with nevirapine and she tolerated the zidovudine, lamivudine and nevirapine regimen well.

Table 2.8 Field diary indicating contact with Participant 4

P 4	19-10-2004	Not available
	22-10-2004	Wanted to discuss research project before deciding. Appointment for 02-11-2004
	08-11-2004	First interview conducted. Appointment for second interview scheduled for 27-11-2004
	22-11-2004	Patient contacted researcher. Had a medical emergency and wanted to conduct interview afterwards. She presented with a skin rash probably due to the antiretroviral drugs. Second interview conducted
	22-01-2005	Appointment for third interview. Moved to 24-01-2005
	24-01-2005	Third interview conducted
	28-02-2005	Appointment for fourth interview. Moved to 01-03-2005 on participant's request.
	01-03-2005	Appointment for fourth interview. Researcher cancelled appointment due to own emergency. Researcher will phone participant later to reschedule appointment.
	07-03-2005	Participant contacted for appointment for fourth interview. Requested researcher to phone 14-03-2005 to schedule appointment.
	14-03-2005	Appointment scheduled for 04-04-2005 due to father's illness.
	04-04-2005	Appointment for fourth interview. Participant not able to attend. Appointment rescheduled for 11-04-2005:
	11-04-2005	Appointment for fourth interview. During call to confirm appointment participant requested that appointments be moved until later stage. Her father is still ill and she has to tend to him after work.



	21-06-2005	Fourth and fifth interview conducted. Due to difficulty securing an appointment, the fourth and fifth appointments were combined. Participant informed regarding conclusion of interviews during this session. Researcher will contact participant for final review of research report at the end of September 2005.
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Participant 5

This participant was recruited while waiting for an appointment with the doctor. She had trouble paying for her medication through the medical aid. The professional nurse and the receptionist addressed the problem. Due to her work and personal commitments she was only available for interviews on one Saturday a month (See Table 2.9).

She initiated antiretroviral therapy in February 2004 with zidovudine, lamivudine and efavirenz; she was ill at the time.

Table 2.9 Field diary indicating contact with Participant 5

P 5	30-11-2004	First interview conducted
	12-02-2004	Second interview conducted
	28-05-2005	Third interview conducted
	02-07-2005	Fourth and fifth interview conducted. Due to difficulty to secure an appointment, the fourth and fifth appointments were combined. Participant informed regarding conclusion of interviews during this session. Researcher will contact participant for final review of research report at the end of September 2005.

Participant 6

Participant 6 was eager to participate in the research project. Work responsibilities, however, led to postponing three appointments. This led to the eventual agreement between the researcher and the participant that the fourth and fifth interviews be conducted at the participant’s office. She was able to provide privacy for the duration of the interviews. The researcher had to cancel one appointment due to a personal

emergency. The participant was informed about the change in plans on the morning of the appointment (See Table 2.10).

The participant initiated antiretroviral therapy with zidovudine, lamivudine and lopinavir/ritonavir. This regimen was changed to zidovudine, lamivudine and efavirenz due to side-effects from the lopinavir/ritonavir combination.

Table 2.10 Field diary indicating contact with Participant 6

P 6	22-10-2004	Participant contacted and agreed to participate in study First appointment set for 11-11-2004
	11-11-2004	Appointment for first interview. On follow-up call to confirm appointment, participant requested that appointment be moved to 19-11-2004 due to urgent meeting
	19-11-2004	First interview conducted
	10-12-2004	Second interview conducted
	27-01-2005	Third interview conducted. Interview could not be recorded due to equipment failure. Notes were taken during the interview by the researcher.
	01-03-2005	Appointment for third interview. Researcher cancelled appointment due to own emergency. Researcher will phone participant later to reschedule appointment
	14-03-2005	Fourth interview conducted at participant's office on her own request. Interview was partially recorded due to equipment failure. The rest of the interview was recorded by means of notes
	16-06-2005	Appointment for fifth interview 20-06-2005
	20-06-2005	Appointment for fifth interview postponed by participant due to work responsibilities
	21-06-2005	Appointment for fifth interview 23-06-2005
	23-06-2005	Fifth interview conducted. Participant informed regarding conclusion of interviews during this session. Researcher will contact participant for final review of research report at the end of September 2005.

Participant 7

This participant was not able to take part in the research in 2004. However, she sounded eager to participate and was therefore contacted again in January 2005. She only cancelled one appointment due to personal obligations (See Table 2.11). She initiated antiretroviral therapy in 2002 with zidovudine, lamivudine and efavirenz. She was ill at the time with tuberculosis meningitis.

Table 2.11 Field diary indicating contact with Participant 7

P 7	November2004:	Requested to be contacted again 04-01-2005 for appointment, currently busy and will then go on leave
	10-01-2004	Not available
	24-01-2004	Not available
	10-02-2005	Agreed to participate. Appointment set for 14-02-2005
	14-02-2005	First interview conducted
	02-04-2005	Second interview conducted
	30-04-2005	Third interview conducted
	21-05-2005	Fourth interview conducted
	18-06-2005	Appointment for fifth interview. Participant cancelled due to personal obligations
	02-07-2005	Fifth interview conducted

Participant 8

Participant 8 indicated that she would take part in the research, but an appointment could never be confirmed.

Participant 9

The ninth participant was reluctant towards joining the research population. She commenced antiretroviral therapy to prevent transmission of HIV to her unborn child. It was difficult to secure an appointment for the first interview and it was cancelled three times by the participant. After the first interview she was once reached per telephone and then indicated that personal circumstances: the baby was due within a weeks time, and moving house, will make it impossible for her to attend further sessions (*See Table 2.12*).

Participant initiated antiretroviral therapy with zidovudine, lamivudine and nevirapine as prophylaxis against mother-to-child transmission of HIV.

Table 2.12 Field diary indicating contact with Participant 9

P 9	21-10-2004	Participant contacted and agreed to participate in study. First appointment set 23-10-2004
	23-10-2004	Appointment cancelled by participant
	29-10-2004	Appointment cancelled by participant
	12-11-2004	Appointment cancelled by participant
	15-11-2004	First interview conducted
	14-01-2005	Participant due for caesarian section 18-01-2005. Moving house at the moment. Participant not available on contact number since then. Participant consequently removed from participant list

Participant 10

This participant seemed to be willing to participate in the research, but it was difficult to secure a first appointment. The second appointment was to be scheduled to coincide with her follow-up appointment at the doctor. She was, however, again not available to either confirm this appointment or schedule another, and was consequently removed from the participant population (*See Table 2.13*).

She commenced therapy with zidovudine, lamivudine and efavirenz in 2001.

Table 2.13 Field diary indicating contact with Participant 10

P 10	21-02-2005	Participant contacted and agreed to participate in study. First appointment set 19-03-2005
	19-03-2005	Appointment for first interview. Participant did not turn up and appointment was moved to 02-04-2005
	02-04-2005	Appointment for first interview. Participant forgot appointment and moved it to 02-04-2005
	16-04-2005	First interview conducted
	25-04-2005	Not available
	26-04-2005	Will call back with doctor's appointment date and time. The second interview will then be conducted afterwards.
	16-05-2005	Not available. Participant removed from participant list due to unavailability

Participant 11

Participant 11 was very eager to participate in the research. Three appointments were postponed prior to the agreed date, due to other commitments on the part of the participant. The third interview was not audio-recorded due to technical failure of the equipment. The researcher took notes during the conversation and explained the change in work process to the participant (See Table 2.14).

She initiated antiretroviral therapy in October 2003 with zidovudine, lamivudine and lopinavir/ritonavir.

Table 2.14 Field diary indicating contact with Participant 11

P 11	22-10-2004	Participant contacted and agreed to participate in study, will come back with appointment time
	15-11-2004	Participant is very busy at work. Requested to be contacted 18-11-2004 to set up appointment
	30-11-2004	First interview conducted
	13-01-2005	Second interview conducted
	11-02-2005	Appointment for third interview. Participant cancelled appointment, moved it to 26-02-2005
	26-02-2005	Third interview conducted. Interview was not audio-recorded due to equipment failure. Researcher took notes during interview.
	19-03-2005	Appointment for fourth interview. Participant cancelled appointment, moved it to 01-04-2005
	01-04-2005	Appointment for fourth interview. Participant cancelled appointment, moved to 02-04-2005
	02-04-2005	Fourth interview conducted
	23-06-2005	Fifth interview conducted. Participant informed regarding conclusion of interviews during this session. Researcher will contact participant for final review of research report at the end of September 2005

Participant 12

The twelfth participant requested that all interviews be conducted at her office. She was able to provide a private area for this purpose. She was very accommodating regarding the scheduling of appointments and never once cancelled or postponed (See Table 2.15).

She commenced antiretroviral therapy in 2001 with zidovudine, lamivudine and efavirenz.

Table 2.15 Field diary indicating contact with Participant 12

P 12	09-11-2004	Participant contacted and agreed to participate in study. First appointment set for 16-11-2004. On participant's request all interviews will be conducted at her office.
	16-11-2004	First interview conducted
	07-12-2004	Second interview conducted
	11-01-2005	Third interview conducted
	11-02-2005	Fourth interview conducted
	15-03-2005	Fifth interview conducted
	29-06-2005	Participant contacted and informed that the sixth interview will not be conducted due to data saturation. Researcher will contact participant for final review of research report at the end of September 2005

2.4 DATA COLLECTION

2.4.1 Data collection settings

Interviews were conducted at the location of the private healthcare facility from which the participants were selected. In general, visits to other locations or the participants' homes, were not advisable as it may compromise confidentiality. Two participants, however, requested that the interviews be conducted at their respective offices. As they were able to provide privacy and they were comfortable with the arrangement, these requests were consented to.

The room at the private healthcare facility where the interviews took place was secured for the duration of the interview to prevent interruptions. It allowed comfortable seating as well as a door(s) and windows that could be closed for privacy.

2.4.2 Data collection process

Interview appointments were scheduled after mutual agreement between the participant and the researcher.

Pleasantries were exchanged at the beginning of each interview. Inquiries were made regarding personal details revealed during the previous interview, for example one participant indicated during the previous interview that she had to prepare an important document for a meeting. The researcher then enquired on the success of that particular task and how she felt about completing it in time. This served the purpose of putting the participant at ease while indicating to her that she, and her feelings and achievements, also matter. Audio-recording was not started at this stage to encourage the participant to relax. However, if she mentioned something important during this time, it was picked up again in the interview, to enable her to elaborate and to record the statement(s).

Except for the first interview, the participant was then presented with a summary of the previous interview. She was allowed time to read through it carefully and was encouraged to discuss any irregularities or differences of opinion.

During the first interview, participants were requested to complete an additional three questionnaires, namely:

- Clinical information
- Demographic information
- The MOS Social Support Survey

These questionnaires were not completed in following interviews.

Completion of the Self-reported Adherence Questionnaire followed next. All previous steps often gave rise to conversation topics regarding adherence and was therefore discussed.

Thereafter the researcher would introduce a statement related to the topic linked to the specific interview (See Appendix G). The participant was encouraged to converse freely about the topic.

2.4.3 Data collection guidelines

Conversations were semi-structured in nature. Participants were asked to describe their experiences and emotions regarding adherence to antiretroviral therapy. These experiences and emotions were not limited to them in person, but were also applicable to what they see or assume other people experience, or how they imagine they will experience a certain situation. For example, some participants never needed to contact their doctor for an emergency after hours, or when he was on leave. They were then asked to imagine and describe what they would do in such a situation.

The researcher repeated important parts of what the participant said to encourage free conversation. This acted to validate the statements and ensured that the researcher understood correctly what the participant meant. It often prompted the participant to elaborate further on the statement.

Participants were brought back to the topic at hand when discussing issues not relevant to the research question.

The researcher attended to non-verbal communication by interpreting and stating it to the participant. The participant could then respond freely to the statement.

A trusting relationship developed between the researcher and the participants during the course of the research. This relationship helped participants to reveal more information later during the research than at the beginning. This enhanced the data collection.

Some participants felt that they had to prepare for the first interview, although it was indicated during the telephone conversation, when the participants were recruited, that this was not necessary. They felt obliged to tell their story and were not very responsive to questions or statements from the researcher. Some others were very reluctant to reveal information during the first interview and mainly kept to 'yes' and 'no' answers. During later interviews, these participants were, however, more willing to elaborate on their answers, given enough response time.

On ethical and professional grounds, participants were also assisted when in need of help or information regarding their HIV treatment.

2.4.4 Data collection methods and procedures

Single site case study was conducted as only one private healthcare facility was used with multiple sub-units representing the different participants. A holistic case study design was used, as each case will be described apart from its own unique experiences, according to the aspects listed in Table 2.16

Each unit of analysis will entail its own technique for data collection as illustrated in Table 2.16 below.

Table 2.16 Aspects according to which each case study was described

UNIT OF ANALYSIS	DATA COLLECTION TECHNIQUE
Unit of Analysis 1: Health Belief Model	Interview Guidelines: Appendix B
Unit of Analysis 2: Adherence level	Questionnaire: Appendix C
Unit of Analysis 3: Perceived social support	Questionnaire: Appendix D
Unit of Analysis 4: Demographic information	Questionnaire: Appendix E
Unit of Analysis 5: Clinical information	Questionnaire: Appendix F Medical file

The Self-reported Questionnaire Assessing Adherence was part of each interview as events in the preceding month could influence the degree of adherence. The MOS Social Support Survey, Demographic Information Questionnaire and Clinical Information Questionnaire were completed during the first interview only. In cases where a dramatic change in social support occurred, the MOS Social Support Survey would have been completed again. This was, however, not necessary. The participants were informed regarding this arrangement before onset of the first interview.

2.4.4.1 Unit of analysis 1: The Health Belief Model

The Health Belief Model is one of several conceptual frameworks developed to explain a patient's belief in the efficacy of treatment, the severity of the disease and social support. These factors, which are seldom assessed in clinical practice, are believed to have more of an impact on adherence than for instance demographic factors. This framework was applied in this study to better understand adherence and adherence behaviour (Brigido *et al.* 2001:591; Durante *et al.* 2003:107-110; Miller & Hays, 2000:[4]; Singh & Squier, 1996:[4-5]).

In this study, the Health Belief Model was used as an interview guide, throughout the data collection phase. Table 2.17 demonstrates how the Health Belief Model had been implemented in the preparation of each interview.

Table 2.17 The Health Belief Model as interview guide

Concepts	Definition	Interview questions	Examples of participant responses
Perceived susceptibility	A participant's opinion of chances to achieve adequate adherence	<p>Interview I</p> <p>Did you have any previous experience with antiretroviral therapy? – How did it go?</p> <p>If you think back to the time you started with the treatment, how did it go the first week?</p> <p>How did you manage to teach yourself to keep to your treatment prescription?</p>	<p>“it’s not easy to forget this, unless you don’t want to drink them. In the early days when I was feeling rebellious, I used to forget them, I wanted to forget them”.</p> <p>“I used to forget, in the first month I forgot a lot, but now ...”.</p> <p>“I noticed is that when I start going beyond the normal time, I almost like develop a headache and I immediately know”.</p>
		<p>Interview V</p> <p>Will it be more difficult to keep to your treatment schedule if you had to take double the amount of pills you are currently taking?</p> <p>Will it be more difficult to keep to your treatment schedule if you had to take your pills more frequently, like three or four times a day?</p>	<p>“The frequency of taking it, it’s fine ... before I started the treatment I was worried that I have to take tablets maybe four times a day, and it was quite refreshing that it is twice a day. And the interval is long enough for me not to be conscious of numbers ... three times is still manageable, but if it’s four times it might be a problem. I think four times is just a bit too frequent. I have to carry a lot more stuff with me”.</p>
Perceived severity	A participant's opinion of the importance of adequate adherence	<p>Interview I</p> <p>For how long will you be taking antiretroviral therapy?</p>	<p>“But I must confess the first few months it was very hard for me. I mean it was very hard to accept that for the rest of my life I’m going to be on therapy. Because generally speaking I’m not a sickly person”.</p>
		<p>Interview II</p> <p>Please comment on the following: The HIV can learn what the anti-HIV medication looks like, and build a defence system around it.</p>	<p>“After a while then the medication will not help, the virus will get used to the medication”.</p>
		<p>Interview IV</p> <p>Who is responsible for raising the kids?</p>	<p>“... in most cases the mother is everything to the child”.</p>



		<p>Interview V</p> <p>What would you consider as reasons to live? Does that influence your adherence?</p>	<p>“There are things that I want to achieve, and if I’m careless about taking my medication, it would be, I’m putting my own life in danger”.</p>
Perceived benefits	A participant’s opinion of the efficacy of antiretroviral therapy and adequate adherence on the impact of HIV	<p>Interview I</p> <p>What do you believe can this treatment do/mean to your?</p>	<p>“The medication is going to make your defence strong. It’s going to help you improve your immune system ... it’s going to prolong your life, it’s going to help to keep you healthier”.</p>
		<p>Interview II</p> <p>The medication control the HIV by ...?</p>	<p>“... the medication will help to suppress and, ah, to avoid opportunistic infections”.</p>
		<p>Interview IV</p> <p>Who is responsible for raising the kids?</p>	<p>“... in most cases the mother is everything to the child”.</p>
		<p>Interview V</p> <p>Can believing that the treatment can help you influence adherence?</p>	<p>“Because you know what, I was so thin. Look at me, I look healthy now. I recovered”.</p>
Perceived barriers	A participant’s opinion of barriers to adequate adherence to antiretroviral therapy	<p>Interview I</p> <p>Identify events or factors that interfered with adherence?</p>	<p>“Usually it happens at night, then I felt, I want to throw up ... I say ah, today I won’t take the second tablet”.</p>
		<p>Interview II</p> <p>Please comment on the following: The side-effects of anti-HIV medication only last for 2 weeks</p>	<p>“If I take those pills before there’s anything in my stomach, it make me dizzy”.</p>
		<p>Interview IV</p> <p>What is your traditional role as a woman?</p>	<p>“Women are naturally nurturing, they will look after their men and ensure or support them in taking medication. Men are not the same”</p>
Cues to action	Strategies to achieve and maintain adequate adherence	<p>Interview I</p> <p>How did you overcome these obstacles?</p>	<p>“... I had to take it three o’clock in the morning so that I sleep a little bit, it dissolves and get whatever. I then wake up and have my breakfast and be able to go to work”.</p>
		<p>Interview II</p> <p>Please comment on the following: I can stop my anti-HIV medication when I don’t feel ill anymore</p>	<p>“It doesn’t mean that when you are OK you can stop, you must always take your medication”.</p>



		<p>Interview III In an ideal world, what should health-care services be like with regards to: Information regarding HIV and related issues</p> <p>Medical aid issues</p> <p>Help you with emotional issues regarding HIV</p>	<p>"It depends also on the information I would get when I'm getting the medication. If they tell me, look, you will expect these, you might experience this, after effects. I'm kind of prepared ... but if I haven't been informed and suddenly there's a change of ... regime, and then I'm having these after-effects, my first , my first inclination is I will call the doctor".</p> <p>"When you had problems with first the medication that was not delivered, was there somebody you could phone to help you sort it out? ... no, it was not easy ... maybe if Felicia were there".</p> <p>"Bring back ... that confidence that has died and the self esteem that has died within them, and tried to get them out of this thing that the disease has been stigmatised and the sense that it is deadly".</p>
		<p>Interview V Would you consider a preparation session before starting on treatment as important?</p>	<p>"It's nice to know so that you can be prepared".</p>
<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Self-efficacy</p>	<p>Confidence in an individual's ability to take action</p>	<p>Interview I Did you have any previous experience with adherence to other medication, i.e. medication for infections?</p>	<p>"I was taking my meningitis ... I was taking Rifafour when I was at home".</p>
		<p>Interview II Please comment on the following: I can never again, for the rest of my life, stop taking anti-HIV medication</p>	<p>"It doesn't mean that when you are OK you can stop, you must always take your medication".</p>
		<p>Interview IV What is your traditional role as a woman?</p>	<p>"If you are not working, you don't have any income or what, you just listen to the boss, the boss is the husband. Because they are the ones who are making the money. Without them you won't survive. So they just listen to them ... I think the problem can be when it's about money".</p>



		<p>Interview V</p> <p>What kind of lifestyle changes did you have to make to accommodate your treatment regime?</p> <p>Do people need to take responsibility for their own health and treatment before they can successfully adhere?</p> <p>Can a positive mindset influence your adherence?</p>	<p>“Personally I don’t like eating in the morning. So I had to learn to eat a particular portion ... have to force yourself”.</p> <p>“Although, at the end of it all, you need to be grown-up about it and you take control again”.</p> <p>“(Do you think that a positive mind can do a lot to keep you healthy?) Exactly, exactly”</p>
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Many aspects influencing adherence, directly or indirectly, were discussed during the interviews. The first four interviews were intended to be audio-recorded and transcribed verbatim for reference purposes. Due to equipment failure, three interviews were recorded in writing. The fifth interview was not recorded but conducted by using a questionnaire. The questionnaire was compiled following initial analysis of the data obtained from all the participants during the first four interviews (See Appendix G).

The topics of the interviews were in accordance with the objectives of the research and were obtained from current literature regarding adherence to antiretroviral therapy. These included the following as summarized under the units of analysis described under 2.4.4 and in Table 2.16:

- Life events improving or hindering adherence (Kemppainen *et al.* 2001:121-125)
- General knowledge regarding adherence and antiretroviral therapy (Tsisis, 2001:110-111)
- Experience of disease progression
- Perception of health-care provision (Van Servellen *et al.* 2002:276-277)
- Experience regarding drug side-effects (Tsisis, 2001:110-111)
- Experience with previous treatment interruption

- Expectations regarding antiretroviral therapy (Tsisis, 2001:110-111)
- On grounds of the researcher's experience and knowledge of adherence to antiretroviral therapy, interaction with patients will take place during interviews to help them find solutions when encountering inadequate adherence. The interaction will be monitored during follow-up interviews.

(See Appendix G).

2.4.4.2 Unit of analysis 2: Level of adherence

The researcher used an existing self-report questionnaire to determine each participant's adherence level and patterns of inadequate adherence (Godin *et al.* 2003:331; Hill *et al.* 2003:521; Simoni *et al.* 2002:433; Turner, 2002:S144; See Appendix B).

The self-report questionnaire was completed during each interview as adherence levels and patterns of adherence may change over time (Gallant & Block, 1998:34; Gross *et al.* 2001:[7]). The study was also specifically designed to run through the major holiday seasons of Christmas and Easter, to allow detection of changes in adherence due to a change in routine.

2.4.4.3 Unit of analysis 3: Perceived social support

Perceived social support is a factor identified by several authors to be an important influence on adherence (Power *et al.* 2003:250; Simoni *et al.* 2002:436-437; Wagner, 2002:605).

As case study research aims to reflect a complete picture of a specific case, it was important to determine the level of social support experienced by the various

participants. This information was then compared to what had been said during the various interviews regarding social support.

The Social Support Survey developed for the Medical Outcomes Study (Sherbourne & Stewart, 1991:709-710) was chosen because it was easy to use, did not take long to complete and was easy to interpret. It also broke social support down into four categories that enabled distinction between the different sources of support. The four categories are:

1. Emotional support
2. Tangible support
3. Positive interaction
4. Affection

The Social Support Survey had been developed for the Medical Outcomes Study investigating the process and outcomes of care for patients with chronic conditions. The items included in the survey were selected to focus on the patient's perception of functional support and represents multiple dimensions of support (Ibid, 1991:705-706).

'For those who trying to understand the etiology and course of chronic diseases, social support must be considered as an important factor that may affect a patient's functioning and well-being.'
(Sherbourne & Stewart, 1991:705).

Internal-consistency reliability estimates of the Social Support Survey in the Medical Outcomes Study were higher than 0.50 for all support measures and proved to be stable over a one-year period. Validity variables include physical functioning, physical role limitations, effects of pain, pain severity, mental health, emotional role limitations, current health, social activity, energy or fatigue, physical symptoms, loneliness, family functioning, family happiness and marital functioning. Of these loneliness and emotional ties correlate highest with social support measures, followed by family and marital functioning and mental health. It is, however, hypothesized that all concepts

are closely related to social support (Sherbourne & Stewart, 1991:707-710).

2.4.4.4 Unit of analysis 4: Demographic information

Demographic information gathered by the questionnaire was validated by data retrieved from the participant's medical file and during the interviews. Current literature on demographic data dictated what information should be collected (Coetzee *et al.* 2004:[4]; Hinkin *et al.* 2004:[4]; Johnson *et al.* 2003:649-651; Kemppainen *et al.* 2001:123-125; Laine *et al.* 2000:[5]; Wagner, 2002:603; Singh & Squier, 1996:[5]).

Relevant demographic data collected, as displayed in Table 2.4, were:

- Age
- Level of education
- Income
- Racial denomination
- Marital status
- Means of payment for health care and medication

2.4.4.5 Unit of analysis 5: Clinical information

2.4.4.5.1 The clinical information questionnaire

Information regarding the HIV infection was also obtained by specially structured questionnaires completed by each participant during the first interview. This information was important because it provided more detail regarding the participant's clinical experiences of HIV infection. For example, was she ill at the time that antiretroviral therapy was commenced? The answer can be a point of initiation during the interview. She can be asked to provide more information regarding how being ill while starting on antiretroviral therapy influenced her adherence. She can also be asked to speculate on the opposite possibility, namely does she think it would be easier or more difficult to adhere if she was healthy? Secondly, the answers to this

questionnaire could be used to validate data revealed by the participant during previous interviews. It also allows limited comparison of information provided by different participants.

2.4.4.5.2 Medical files and records

During the first interview participants were asked permission to obtain medical and treatment related history from their respective medical files and participant recollection. Each participant completed an informed consent form before any data collection commenced. This information included all previous laboratory testing results including immune status, toxicity and side-effects. It also included the reports of physical examinations and other special investigations ordered by the treating physician, for example X-rays. Each participant was requested to converse, mainly during the first interview, about her medical history regarding HIV.

2.5 MEASURES TO ENSURE VALIDITY AND RELIABILITY

The following strategies as described by Miles and Huberman (Burns & Grove: 1997:338-339) were employed in the study to ensure validity:

- The presence of the researcher can influence behaviour and lead to collecting invalid data. This effect will be counteracted by the researcher staying long enough on site to become familiar to the participant/s (Burns & Grove, 1997:338). The study will continue for at least six months but the data collected for any patient leaving the study before completion will still be reported.
- Data from different sources will be compared to determine **construct validity**

(Burns & Grove, 1997:338; Yin, 2003:35-36). In this study information will be gathered from conversations, patient files and measuring instruments. Interviews were also conducted with the professional nurse and the doctor at the healthcare facility, regarding patient adherence.

- Construct validity was also obtained by presenting a summary of each interview to the specific participant at the beginning of the next one. Participants were encouraged to voice any uncertainties or disagreements. It was then noted in the original transcript copy. The fifth interview was structured as an open-ended questionnaire derived from a preliminary data analysis of the first four interviews of all the participants combined. The purpose of this questionnaire was mainly to validate the data already discussed in previous interviews. It also allows participants who did not previously have the opportunity to comment on the specific statement, due to the nature of their individual interviews, to give an opinion.
- Although casual claims are not part of the descriptive case study, inferences made by the researcher about events that cannot be directly observed can threaten *internal validity*. Therefore all data captured will be presented to the patients individually to determine the strength and accuracy of each finding (Burns & Grove, 1997:338; Yin, 2003:36).
- Each patient's level of adherence will be determined at the onset of each interview. This will form part of her history and context. This will also enable the researcher to compare findings for differences and similarities (Burns & Grove, 1997:338).
- According to previous surveys and studies, women and black people are associated with poorer adherence. Although the aim of this study is not to prove or disprove this hypothesis, this population may provide unique findings (Burns & Grove, 1997:338).

The study is not designed around a specific hypothesis, but is rather exploratory in nature. A hypothesis may develop from the findings or the results could be

generalized to some broader theory through analytical generalization. This will attend to the issue of **external validity** regarding case studies (Burns & Grove, 1997:339; Yin, 2003:37).

Strict following of protocol will adhere to **reliability**. All conversations will be audio-recorded and transcribed verbatim. Measuring instruments and copies of patient files will be kept for reference purposes. The researcher will keep a field diary to note special events and appointments with each participant.

2.6 DATA ANALYSIS

2.6.1 Getting to know the data

All recorded interviews were transcribed verbatim. The documented data obtained during the non-audio recordings and the last questionnaire-driven interviews were added to the transcripts.

Recordings and notes were revisited and attention was paid to intonation and non-verbal responses. These impressions were noted in the transcripts (Taylor-Powell & Renner, 2003:2).

The transcripts were then examined for all sentences or phrases regarding adherence. No effort has yet been made to determine the value of these phrases. Each phrase was then marked with a code indicating the participant's study identification number and the number of the interview. This will facilitate easy reference to transcribed data when needed (*See Figure 2.5*).

"I always make sure that I have an extra dosage just in case[1/3] if for one reason or the other I'm not able to come back when I need to."

Figure 2.5 Example of phrases regarding adherence marked in the transcripts and documented data

The appropriate phrases were underlined while the code, in square brackets, firstly indicates the participant's study identification number and secondly the interview number (*See Appendix I*).

2.6.2 Categorize the information

Once all the data was marked the phrases were extracted. Each phrase was printed on a separate card. Statements with a similar meaning were grouped together. This process was repeated until no cards were left. Small groups were then evaluated for incorporation into larger groups while extremely large groups were sub-divided into smaller groups. When all the phrases were grouped satisfactorily a heading was generated for each group. Smaller groups were then grouped into larger groups. Larger groups were then grouped into larger themes (Taylor-Powell & Renner, 2003:2; *See Appendix J*).

2.6.3 Focus the analysis

The analysis was then focused by deciding upon key questions designed to answer the research question (Taylor-Powell & Renner, 2003:2).

- Which real or potential factors inhibit adherence to antiretroviral therapy?

- Which real or potential factors enhance adherence to antiretroviral therapy?

Each of the headings describing the content of a group was then assigned to a key question. The heading was then marked with the key question code describing it best. In case where more than one key question applied, both codes were proposed. This was important so as to distinguish nuances between experiences of the same situation by different participants.

2.6.4 Identify patterns and connections within and between categories

All the data pertaining to a specific heading was then analyzed for patterns indicating similarities and differences. All subtle variations to these were also noted (Taylor-Powell & Renner, 2003:5).

Lastly, all the data was searched for relationships between categories. It may be important to know that the combination of certain factors may be more important than the factors in isolation (Taylor-Powell & Renner, 2003:5). For example: Financial independence may enable a woman to adhere to her treatment regime because she need not ask her partner for financial support. However, this factor becomes more pronounced when the partner does not approve of the woman being on antiretroviral therapy. On the other hand, if the partner is supporting the woman in her treatment, this factor loses its potency.

2.6.5 Interpretation

The research data was interpreted according to the themes, relationships and patterns identified in the previous four steps (Taylor-Powell & Renner, 2003:5).

Similarities and differences within literature were identified. The data was then discussed at the hand of available literature.

2.7 ETHICAL CONSIDERATIONS

The researcher complied with the guidelines as stipulated in the ***Faculty of Health Sciences Research Ethics Committee Package S193/2004*** (See Appendix K). The protocol submitted will be adhered to and any variation from it will be motivated by the researcher.

Letter of intent and informed consent

Each participant received a letter informing her about the goals and policy of the research. Confidentiality was especially stressed. She was requested to sign an informed consent document to protect both the researcher and the participant.

When each of the participants was invited to take part in the research, they were informed of the purpose and rules of the research. The informed consent was signed at the beginning of the first interview. The participants were allowed time to read the information letter containing the goals and policy of the research. The written informed consent did not specifically requested consent to access the participants' medical files, however, oral consent was obtained prior to the first interview, and no participant refused this access. The researcher was available to answer any questions. Each participant was offered a copy of the informed consent, although some chose not to take it.

Permission was obtained from the concerned authorities to conduct research.

2.8 LIMITATIONS OF THE STUDY

The study was limited to only one private healthcare facility and only to Black women on antiretroviral therapy. Some new data may come to light when the same research is conducted in other private healthcare facilities, especially when structured differently than the one used, for example private healthcare clinics. It would also be interesting to obtain data from participants receiving antiretroviral therapy from public hospitals and clinics. Participants from other race and gender groups can also reveal some interesting facts.

2.9 CONCLUSION

In this chapter the following was discussed:

1. Research design
2. Data collection instruments and procedures
3. Process of data analysis
4. Ethical considerations
5. Limitations of the study and recommendations for further research



CHAPTER 3

REPRESENTATION AND DISCUSSION OF DATA

3.1 INTRODUCTION

The process used to analyse the data obtained during the data collection phase was extensively discussed in chapter 2. In this chapter the analysed data will be presented and discussed in relation to existing literature on adherence to antiretroviral therapy.

3.2 DATA ANALYSIS PROCESS

The data obtained through interviews with participants was transcribed verbatim. Data obtained from interviews which were not recorded, were documented and summarized. The data was then scrutinized for any phrases relevant to adherence to antiretroviral therapy. These phrases were extracted from the original bulk of data and sorted according to themes. Smaller groups were combined to form larger groups, while large groups were subdivided to form smaller groups. The data was then searched for themes that answered the research question, namely:

Factors associated with adherence to antiretroviral therapy for the treatment of HIV infected women attending an urban private healthcare facility



Themes were then grouped to form sub-categories and finally to form the three broad categories answering the research question, namely:

- 1. Real or potential factors enhancing adherence to antiretroviral therapy**
- 2. Real or potential factors inhibiting adherence to antiretroviral therapy**

(See Figure 3.1)

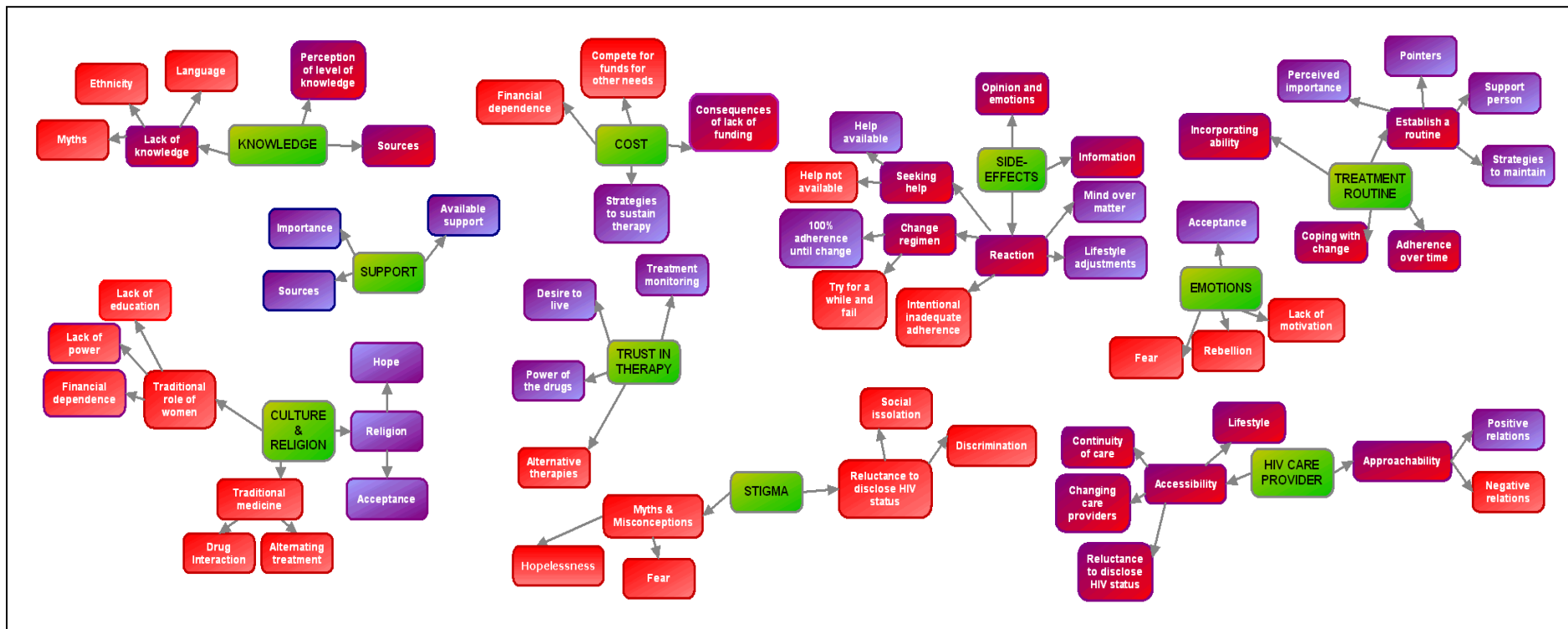


Figure 3 Factors that influenced or might influence adherence to antiretroviral therapy

3.3 BACKGROUND ON PERSONNEL WORKING AT PRIVATE HEALTHCARE FACILITY

At the private health care facility at which the research was conducted, several people were involved in the care of HIV positive patients. A doctor specialized in internal medicine and infectious diseases were primarily responsible for the patients' care. He was assisted by a professional nurse experienced in the clinical and administrative details of HIV treatment. The receptionist was mostly aware of the HIV patients who visit the facility and helped from time to time with administrative duties, for example registration at the medical aid HIV management program. The filing clerk was responsible for filing laboratory results, but also assisted with interpretation and translation in cases where language seemed to be a problem (*See 2.3.1.1*).

3.4 BACKGROUND INFORMATION ON PARTICIPANTS

Clinical Information

The participants included in this study were in different phases of their HIV disease, displaying different immunological status and varying responses to antiretroviral therapy. Some participants were on antiretroviral therapy for several years while others commenced therapy only recently. Of the participants on the study, seven were still on the same regimen they started off with. Of the remaining four participants, probable resistance was the reason for one to change therapy, while the other three were switched from their previous regimens due to intolerable side-effects. Although the first participant mentioned had to change her therapy because of probable resistance, she later also had to change it again because of severe side-effects (*See 2.2.1.1./Documents*).

Demographic Information

All participants in the study were working and generated a monthly income. Only two participants paid for their therapy solely from their own funds, while the other nine made use of partial or complete financial support from a medical aid or their employer. Monthly income, however, varied greatly amongst participants. Age groups included in the study range from 18 to 49 and several ethnic groups were represented. One participant was born and raised outside South Africa but has already lived in the country for several years at the time of the study (*See 2.3.3.2*).

3.5 LITERATURE VERIFICATION

During the literature overview, several shortcomings regarding adherence to antiretroviral therapy in the South African context, and particularly amongst black women, were identified. The study aimed to identify all factors that influenced the adherence of a sample of black women attending an urban private healthcare facility.

The data obtained may:

- Elucidate factors not previously identified or explained by research
- Identify similarities with previous research
- Identify inconsistencies with previous research

3.6 PARTICIPANT VERIFICATION

Information obtained from participants was compared to information obtained from their medical files, the Self-Reported Questionnaire Assessing Adherence, The MOS Social Support Survey, the demographic and the clinical information questionnaires. At the onset of each interview, a summary of the previous interview was also presented to each participant for verification and clarification purposes. The last

interview was constructed from joint responses obtained from all participants and all completed interviews. This was done firstly to verify information already provided as well as to facilitate responses from other participants who did not previously discuss a specific issue.

3.7 DATA ANALYSIS

3.7.1 Culture and religion

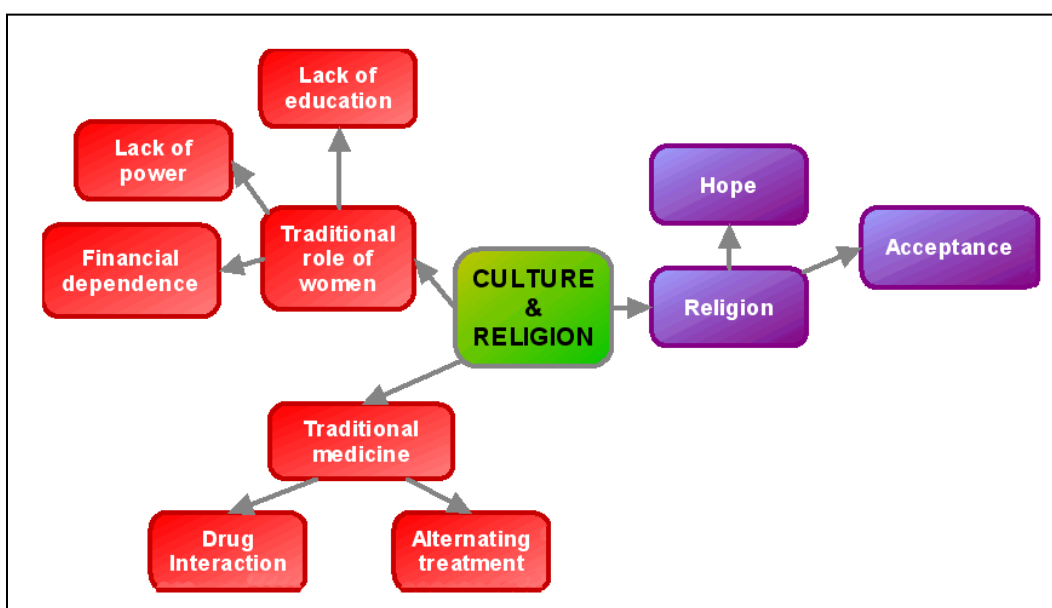


Figure 3.1.1 Aspects of culture and religion as it influenced or may influence adherence

Culture and religion play an intricate role in the lives of many people, whether diagnosed with HIV or not. On a daily basis, it influences the way a person thinks and conduct herself.

Hefner (1998: 536, 541) describes culture as behavioural information essential for human survival. Religion on the other hand is an informational base within culture.

Religion has the function of recognizing what the world can become and thus directing the decisions and views that guide culture.

One participant pointed out that religion, rather than culture, dictates people's behaviour and the decisions they make.

“... religion influence me ...”

“...something they do are connected to their culture, now they are Christians, then they leave some of the things of the culture out ...”

Religion and culture are, however, interconnected and can not be separated.

“... it's more like around religion, rather than culture. It's interlinked ...”

During the data collection phase, no participant reflected that a specific incident of religion or culture directly influenced their adherence to antiretroviral therapy.

“... (*is there anything in your culture that clashes with what we tell you to do regarding the medication?*) ... not as far as I know ...”

In order to explore these two factors further, participants were asked to discuss religion and culture in terms of how it might influence adherence in circumstances different from their own. For instance, all participants in this study indicated that they were, to some extent, free to make their own choices and that their husbands or partners approved of them utilizing antiretroviral therapy. A woman who are not allowed to make her own choices due to cultural or religious instructions, and whose husband or partner does not approve of her using antiretroviral therapy, may experience difficulty with adherence and obtaining the medication.

3.7.1.1 Religion facilitate hope and acceptance

Religion played an important role in many participants' lives. Initially it helped them to come to terms with being HIV positive. Acceptance is an important factor in achieving adequate adherence (See 3.7.2.3).

Spiritual resources play an important role in the achievement of hope and the physical health and wellbeing of people living with HIV (Pargament, McCarthy, Shah, Ano, Tarakeshwar, Wachholtz, Serrine, Vasconcelles, Murray-Swank, Locher & Duggan, 2004:1206-1207).

Clarke (2003:164-165) describes hope as inspirations and vitality. At the same time creates the loss of hope a lack of eagerness, desire, certainty about the future and a loss of "meaning and purpose of life". Faith, on the other hand, helps people to make sense of the world, and acts as basis for daily decisions.

Hope is an important factor in a person's adjustment to a serious event such as relevant in living with HIV. Certain hopes will be unrealistic and therefore become unattainable, for instance having children or living to old age. However, a general attitude of hope and optimism will sustain a person through the necessary psychological adjustments (Clarke, 2003:165).

In their study, Douglass *et al.* (2003:11) observed a correlation between hope and adherence. Inadequate adherence was associated with a loss of hope.

Kylmä, Vehviläinen-Julkunen and Lähdevirta (2001:767-9) conducted a study examining the dynamics of hope in people living with HIV. Becoming HIV positive, changes the balances and hopes that exist in a person's life. These changes could be summarized as **losing** or **receiving**. **Losing** could comprise of factors such as loss of potential parenthood, while **receiving** could include becoming a stronger person or experiencing and valuing life from a different perspective.

One participant reported despair at the time she was diagnosed with HIV. She reverted to religion.

“I sat, I was tired, because I really think, I prayed, cried and fell asleep ... I was really miserable ...”

As time went by, religion also served as a source of strength to her, and many other participants.

“I just prayed to God to make me strong ...”

One participant was even convinced that her involvement in the church and her relationship with God is a consequence of her being HIV positive.

“... accept whatever happened, and embrace it, because it's something that can bring you closer to God ... I actually accepted it and entered the debate where I said, haven't I been positive, would I be this involved in the church?”

Some participants saw being HIV positive as a second chance on life. The diagnosis of HIV reminded them that life is precious and should not be wasted.

“I refuse to die ... I feel this is a second chance ... so the fact that I know, that I got this, and it make me realise that whatever, however more everything that I'm doing or I'm thinking of, it has to be important ...”

“... like a second chance at life ... so I then live it to the full and make the most of it ... I don't see it as a death sentence ... that would kind of have that effect to kind of speed up your death ...”

“... it's something I'm compassionate about ... it's meant I should review my life, look at another direction in my life ... AIDS is not going to stop me. Only death is going to stop me ...”

Although not specifically discussed in this study, if religion can induce or facilitate hope, it might play a role in counteracting depression and feelings of hopelessness. It may therefore indirectly promote adherence. Mellins *et al.* (2003:409, 411) described that 50% of the participants in their study, examining the psychosocial predictors of adherence among mothers living with HIV, presented with psychiatric disorders commonly found in HIV positive women. These factors included major depression,

other depressions, panic, post-traumatic stress disorder, other anxiety disorders and psychosis.

The relation between depression and inadequate adherence were described abundantly in literature. According to several authors depression is one of the few factors consistently associated with inadequate adherence (Van Servellen *et al.* 2002:277; Simoni *et al.* 2002:432; Paterson *et al.* 2000:27-28; Singh & Squier, 1996:[4, 6]; Wagner, 2002:602-5; Johnson *et al.* 2003:649-651).

“... whenever I have a problem, I feel today I'm really down, I pray ...”

Participants voiced different religious beliefs during the interviews. None of these beliefs were, however, reported to directly impact adherence. The study did not include participants of all religious groups instituted in South Africa. There may therefore be religious beliefs that interfere with adherence to antiretroviral therapy that were not identified in this study.

The notion that God can cure HIV was held by one particular participant, although she did not solely rely on this belief. It subsequently did not threaten her adherence to antiretroviral therapy.

“I believe it can be cured from God.”

Another participant was aware of this belief, but did not compromise her antiretroviral therapy for it.

“... there are others who believe, they are praying and you can go and do your test and you'll find that you are HIV negative, and people they go there because they want to believe ...”

3.7.1.2 Traditional medicine

Only two participants reported that they once visited a *sangoma* (traditional healer) regarding their HIV infection. Both used the medicine they received as a cure for HIV infection. One of these participants expressed confidence in the traditional medicine and said she would consider utilizing this service again.

“... (*are you going to a traditional healer?*) ... ja, first time I was there, but now, I'm not going anymore ... it helps me ...”

However, the other participant explained that she would not again utilize the services of a traditional healer, as it did not help.

“... previously I went for that medicine, but then it didn't help me ...”

Rowe, Makhubele, Hargreaves, Porter, Hausler and Pronyk (2005:266) found that participants in their study put more trust in traditional medicine as traditional healers claim to be able to heal HIV, while western medicine proclaim that it is only able to slow down the process of HIV. Some participants, in their study, indicated that they would therefore rather revert to traditional medicine.

“... because the traditional doctors he can give you a medicine ... that medicine, it can clean all that virus in your blood, and give you the new blood. So it helps ...”

A belief that traditional medicine can cure or contain HIV can influence adherence in mainly two ways. Firstly, there may be an interaction between the traditional medicine and the antiretroviral drugs. This may cause an increase or a decline in the levels of the antiretroviral drugs. Increased drug levels can cause toxicity while decreased drug levels may lead to emergence of virus resistance (Hoffmann *et al.* 2005:698-699).

If the traditional medicine causes diarrhoea or vomiting, the drug level of the antiretroviral drugs will also decline due to reduced absorption time. This may lead to unintentional or unknowing inadequate adherence, as the patient did not decide not to

take the antiretroviral drugs, but through her behaviour interfered with the absorption thereof. This kind of interference with adherence again emphasises the importance of disease and treatment related literacy.

Secondly, patients may prefer not to take the western medicine in favour of the traditional, or may decide to combine the two haphazardously. Some people believed that medication from the traditional healer and antiretroviral drugs should not be taken simultaneously. This can lead to interruption of antiretroviral therapy whenever the person needs to take the traditional medicine (Rowe *et al.* 2005:266).

In a study conducted in three private clinics in Botswana to determine barriers of adherence to antiretroviral therapy, Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Kgosidialwa, Essex and Marlink found that 47% of interviewed participants used traditional remedies for HIV in the past. Most patients (92%) however preferred western medicine while 21% of patients indicated that they might visit a traditional healer for their HIV infection, in the future. The use of traditional medicine was found not to have an impact on adherence (2003:283-284).

Most participants in this study indicated that they would rather revert to western medicine. The most prominent motivation seemed to be the level of control and testing associated with western medicine (Weiser *et al.* 2003:283-284).

A South African study determining the health seeking behaviour among tuberculosis patients, established that 72% of patients reverted to health clinics or hospitals as their first choice for medical care. Some patients (15.4%) preferred to utilize the services of a traditional or spiritual healer (Pronyk, Makhubele, Hargreaves, Tollman & Hausler, 2001:[7]).

“When it comes to culturally thinking that medication from a sangoma will heal me ... I don't believe in that ...”

However, several participants indicated that traditional medicine might become an option when all the resources of western medicine are exhausted.

“Maybe I reached the end ... and there is 0.001 percent chance ... if you go to a traditional healer and this will happen, then you will be healed. Then I'll say, OK, I've nothing to loose, I'll take it.”

3.7.1.3 The traditional role of women

Some participants indicated that most black women in Africa have traditionally little or no say in family life. Buvé, Bishikwabo-Nsarhaza and Mutangadura (2002:2013-2014) reported on the spread and impact of HIV in sub-Saharan Africa, that women are in many instances subordinate to men. Women are not supposed to know anything about sex, are required to have little pre-marital sexual experience and are expected to be faithful in marriage. Men are, however, ‘expected’ to have pre-marital and extramarital sexual relationships. They supposedly know everything and their decisions are not to be questioned. To enforce these traditional values, women have to endure restrictions regarding access to education, owning of property and employment. Women are consequently generally economically dependent on their male partners or relatives. This dependence put them in a vulnerable position when negotiating safe sexual practices (Bacchus, 2002:10).

“... because you are female, with this culture thing, always thinks that men know more than females ...”

“... they don't have a say at all ...”

“Many black women are very dependable on their men. They will do whatever he say should be done. They would leave their kids, even if it is his kids, to stay with him, if that is what he says. They will have sex without a condom rather than take the risk of him leaving her for another women. I'm not like that, because I know better ...”

“... she would drown herself if he tells her to ...”

“... the conditioning that people get brought up in, it's kind of implied in there, in our upbringing, that yes the man is the head of the house, and you submit to him and all that ... but really at some stage, if those thinkings become a cage, really we must move with the times ...”

Adherence can thus be unfavourably influenced in situations where the head of the household, the husband or partner, does not agree or does not believe in antiretroviral therapy.

“... black men want to be in control of their relationships ... the woman is subordinate to her husband ... it might happen that a woman will not be able to adhere to these guidelines ... even modern westernised black women still have to follow the social rules of tradition. The man is still the head of the house in most families ... black men are not likely to engage in counselling ...”

“... especially those men from rural areas, they still say ... but it also has to do with the culture. You'll find that he is educated, but he is still making the rules ... even in terms of lifestyle, the way you are living, he can tell you, no, you are a woman, you are suppose to do this, you must bring your salary ... all those things, you know. It has a lot to do with the way they grow up at their home ...”

It may also have an impact on the use of antiretroviral therapy in the prevention of mother-to-child transmission of HIV. As part of this prevention, women are required to undergo a caesarean section and to abstain from breastfeeding. However, these practices might be considered culturally unacceptable.

“... she is not woman enough if it's not natural. She is taking the easy way out if she goes for a caesarean section ...”

Health care providers should attend to the possibility that women who are used to a submissive role may not ask questions when they do not understand something related to their treatment or HIV. They are used to do as they are told and not to ask questions or question motives. This can present a problem when the health care provider is under the impression that patients understand what is expected of them, while it is actually not true.

“... you also find it in the Zulu culture. If the boss says something, they just say yes ...”

However, some participants indicated that although this was the norm, they do not strictly follow the rules. There may thus be different degrees to which women adhere to their traditional roles.

Bacchus (2002:2, 7) reported that although the knowledge and awareness of HIV in Africa increased over the past few years, there is not yet a significant change in behaviour and attitude towards the disease. The continued increase in incidence and prevalence in sub-Saharan Africa is evidence of this. The functionality of adult literacy is a product of a person's view of the world, literacy and knowledge with emphasis on relevancy of the literature on one's social reality. Literacy is a prerequisite for obtaining education and knowledge.

Education in general, as well as disease and treatment related literacy, have a positive influence on adherence. It gives people the opportunity to re-evaluate and amend their traditional beliefs by making informed choices. Although many would still prefer the traditional way because it is familiar and suits their purposes, some will refrain from traditional practices because of what they have learned through education.

"... it depends on one's upbringing and factors, your thinking, your level of interaction with ... you level of education ..."

"... although they are educated and know what is going on, that they will then go to traditional healers ..."

"... on one hand you have to do with culture, on the other one it has also to do with the level of education ..."

"Culture definitely underlies what we do, the difference is to what degree does it determine what she do. But I would be naïve to think that simply because people are educated, culture doesn't influence what they are doing, it's not true."

"... with an uneducated or poorly educated black man, culture will play the stronger part and not the education, because they don't necessarily understand all the risk associated with this kind of behaviour ..."

"... the determinants is your level of education and the practicality of what you're expected to do. That it makes sense. If it makes sense, and its culture, you would go ahead and do it. But if it doesn't make sense, your level of education enables you to make the judgement call ..."

"Their level of education enables them to understand the issues. But because they are traditionalists ... when it comes to, for instance negotiating the use of a condom, that's where the culture comes into it ... it's what you want to believe ..."

More and more women are being educated beyond school level. Education enables a person to secure employment which in turn generates an income. In the first place, being educated provides a person value and self-confidence, and contrary to many traditional beliefs, she now has a voice of her own. Secondly, securing an income generate financial independence to further provide freedom to act on what she believes.

“(Do you think it helps if a woman is educated and a little bit independent) ... definitely, it does ... give her confidence to say, listen, I don’t like what’s going on here, I’m not going to do this ... then you are not in a sub-servant role where you are dependent on the other person who then determine the rules of the game, because then what options do you have?”

“... a woman who is dependent to a man, opens herself up to abuse. A woman who is independent, threatens her man’s ego ... a woman is generally not allowed to speak her mind ...”

“... (women like you, who can stand on their own, are in the minority?) ... Yes”

With women becoming more educated and securing more important positions in the workplace, things are starting to change. Some participants indicated that they were not subjected to the rules of tradition, and that their partners or husbands were supportive and understanding. Bacchus (2002:12) describes the functionality of literacy as a change in world views. As culture and religion influences the way we see our world, literacy can influence the way we perceive and experience religion and culture.

“But it depends, things are changing, you know, some men are different ...”

“... (safe sex, do you think it would be difficult for you to negotiate?) ... it’s not an issue for me, definitely not. That if it wasn’t my kind of partner that I have, even my personality ... I wouldn’t go out with somebody like that. No it’s not negotiable for me ...”

“I did tell him that I would go for a caesarean maybe it can help a lot for the baby not to be affected. But he doesn’t have a problem with that ...”

“I’m not like that, saying the man is the boss. I can’t just say yes to everything he say ... at the end of the day he understand the situation ...”

“...his word is law? ... NO!”

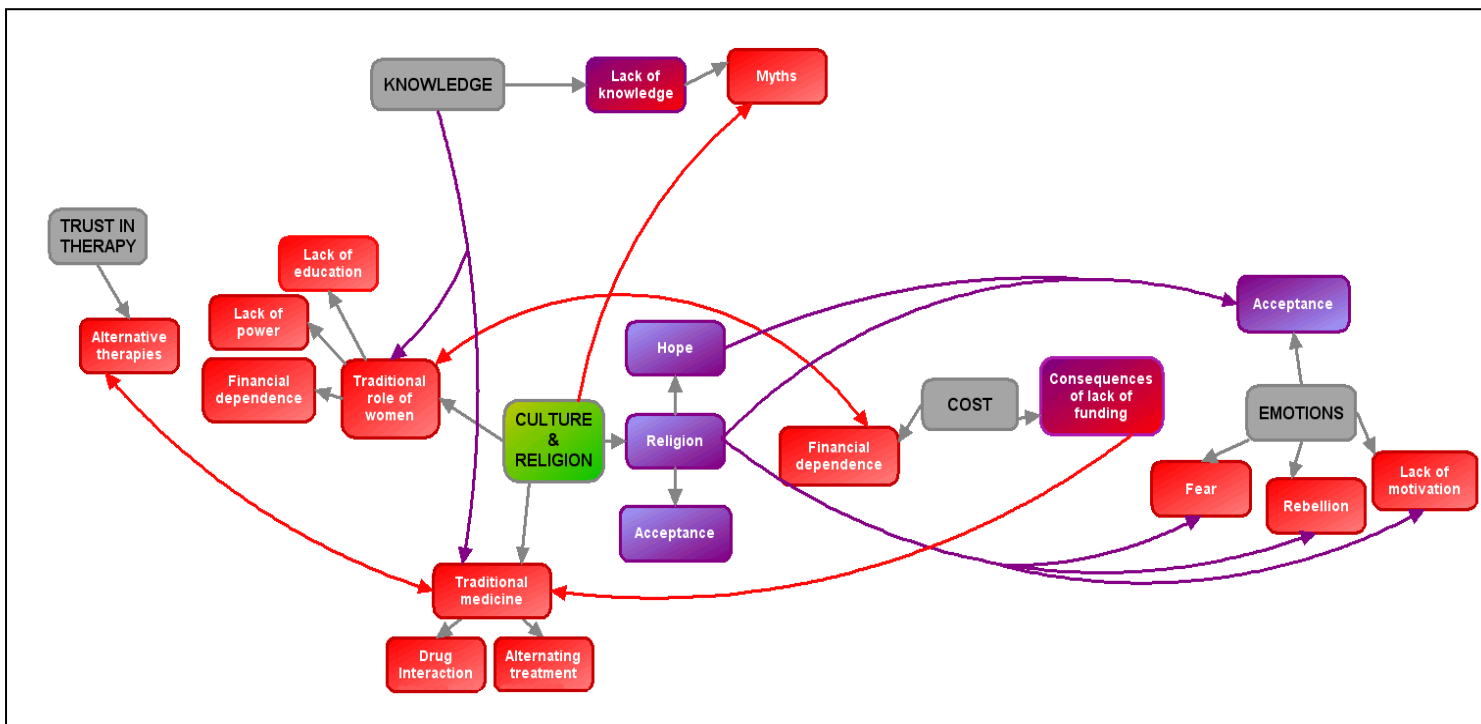


Figure 3.1.2 Aspects of culture and religion as it influenced or might influence adherence in context

3.7.2 Emotions regarding HIV and its treatment

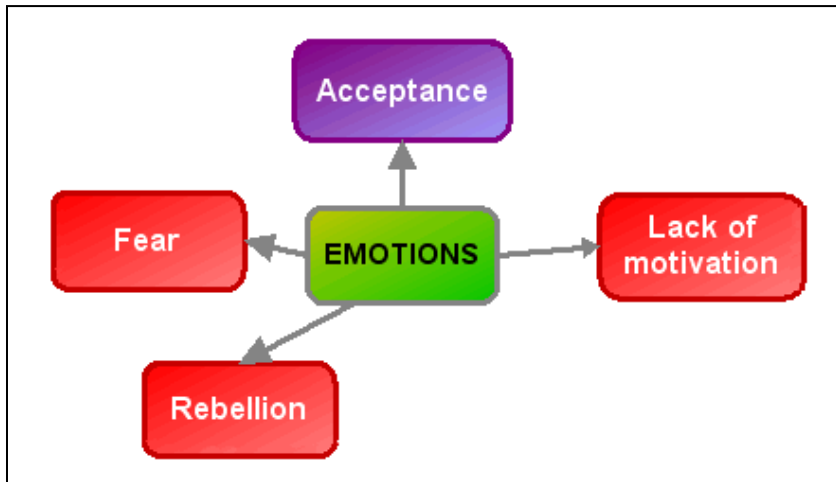


Figure 3.2.1 Aspects of emotions as it influenced or might influence adherence

The women included in this study did not try to deny their emotions of sadness, anger, shock, resentment and disbelief. They described it as ...

“I was sad, I was scared I thought I was going to die ...”

“... sometimes in the past I broke down and cry ...”

“I was angry.”

“I was devastated. I never thought it could happen to me ... based on my lifestyle anyway. I mean I’m a one ... my relationship is with one person. And I stayed with one person not knowing that I would be infected.”

“... you know that you are, you’re faithful, but when something like this happen, then you sort of like get scared as well that what if he says it’s not him ... knowing very well that you’ve done nothing ...”

Bunting (Jones, 2005) developed a grounded theory from interviews with HIV positive patients. The participants were asked to express their experiences regarding taking antiretroviral therapy. She found that most participants tend to create a ‘normal’ socio-psychological environment in order to cope with the diagnosis of HIV and its treatment.

Better emotional adjustment to being HIV positive was associated with a more active behavioural coping style, whereas avoidance were associated with poorer adjustment to HIV (Gore-Felton, Rotheram-Borus, Weinhardt, Kelly, Lightfoot, Kirshenbaum, Johnson, Chesney, Catz, Ehrhardt, Remien, Morin & the NIMH Healthy Living Project Team, 2005: 25).

One of the factors identified by De Bruin, Hospers, Van den Borne, Kok and Prins (2005:391) to adversely interfere with adherence was a lack of motivation.

Little information regarding specific emotions and their impact on adherence to antiretroviral therapy is currently available in the literature.

3.7.2.1 Fear

Most participants reported that at some stage since they received their diagnosis, they have experienced some form of fear. To some it was a daily companion:

“I don’t want flu at all. I panic. I make sure I get my medication ...”

“... every time I was sick I would rush, you know, I just didn’t want to ... even if it was a little thing ...”

“... whenever, ever I have a headache, I would come to * to see if everything is OK ...”

Others only experienced a flash of fear when confronted with a particularly dire situation related to HIV or antiretroviral therapy.

Holzemer reported in an interview with Tobias (1998)³ from Bulletin of Experimental Treatments for AIDS, that although fear was not a prominent factor amongst ‘healthy’

³ Information obtained from an interview with Holzemer, W after the 12th World AIDS Conference in July 1998. Interview published on Bulletin for Experimental Treatments for AIDS 1998
<http://www.sfaf.org/treatment/beta/b39/b39holzemer.html>

HIV positive patients and therefore did not influence their adherence, it may influence adherence in patients who are clinically ill due to their HIV infection.

According to Kylmä *et al.* (2003:770) patients can experience different fears related to HIV. These include the fears of:

- Disclosure of HIV status
- Rejection
- Losing a child
- HIV progression
- Transmitting HIV to a partner
- Changes in manner of obtaining HVI medication
- Changes in quality of medical care
- Death

Patients who have a sustained severe experience of fear might experience interference with their adherence.

“... you become anxious sometimes that, especially I get ... when I see people, you know when they are in their last days and they are really, really sick, they loose weight and they can't do things, sometimes it upsets me. Knowing my days near, I'm going to be like that ...”

“I was here last week and this person was this big and I was here this week and this person was this thin ...”

“... then why are people dying ... that's what scares me ...”

“... people are dying around me from the same disease ...”

“... a lot of people look healthy. A lot of people are healthy, but we know that ... statistics say one in every five persons should be HIV positive ...”

Several participants indicated that fear were most prominent in the period when they received their diagnosis. This sprouted mostly from a lack of knowledge regarding HIV and its treatment. As they gathered more information regarding the disease and its treatment, the fear gradually subsided. . The most significant remark was probably

that fear can prevent a patient to start antiretroviral therapy. Health care workers should particularly be attentive for signs of fear and anxiety that might interfere with a patient's ability to adhere.

Fear combined with uncertainty, a product of ignorance, is connected to despair and hopelessness (Kylmä *et al.* 2003:773).

“... because at that stage I was got so frightened, then I thought maybe, because those days it was like you can die tomorrow ...”

“... for the first time I was scared. But now I'm free, I'm really free ... I thought if I have this disease I'm going to die ... and then I leave my family and my child ... I was very scared ...”

If a patient's fear is directed towards the efficacy or probable harmful aspects of antiretroviral drugs, it can interfere with adherence. Fear, suspicion and scepticism towards antiretroviral therapy were some of the emotions identified by Gore-Felton, Vosvick, Power, Koopman, Ashton, Bachmann, Israelski & Spiegel (Gore-Felton *et al.* 2005:27-28).

However, fear can also be directed towards the stigma enveloping HIV. Patients' fear that their status may be revealed; interfere with adherence and even prevent a patient to commence treatment. Refer to the discussion regarding stigma in 3.7.9.

“... fear, not HIV/AIDS kills. Fear can cause a person not to go onto treatment ...”

All participants, in the study conducted by Weiser *et al.* (2005:266) indicated that their fear of being discriminated against because of their HIV status, may interfere with their adherence.

The fear of possible detection and subsequent discrimination when their HIV status becomes known, prevented or delayed participants in several studies from doing blood tests and refill their medication (Kylmä *et al.* 2003:285; Mallinson, Relf, Dekker, Dolan, Darcey & Ford , 2005:269).

One participant in this study indicated that this fear of disclosure may prevent many patients from seeking information and even clinical help, such as antiretroviral therapy. The influence of health care and disease related knowledge on adherence are extensively discussed in 3.7.8.

“... maybe it was a part of me that was scared. Because whenever I saw a paper, a newspaper with HIV, and then I will not read that part ...”

“... it's funny, before I had no problem, I didn't know my status, I didn't have a problem to go and look, stare at that board and look at what is happening, but now I can't even go ...”

3.7.2.2 Rebellion

Prior to accepting her diagnosis and the fact that she needed to commence treatment, one participant reported that she intentionally interrupted her treatment due to feelings of rebellion.

“... it's not easy to forget this, unless you don't want to drink them. In the early days when I was feeling rebellious, I used to forget hem, I wanted to forget them ...”

In a report discussing adherence to chronic diseases in general, poor adherence is identified as a possible way in which patients can rebel against the control the treatment or disease took over their lives (Anon. 2003:220).

3.7.2.3 Acceptance

Acceptance was singled out by several participants as an important prerequisite for maintaining uninterrupted treatment. Ngamvithayapong, Uthavivoravit, Yanai, Akarasewi & Sawanpanyalert (Rowe *et al.* 2005:267) found in their study that acceptance of a person's HIV status to be important to improve adherence. However, Lerner (Rowe *et al.* 2005:269) found that acceptance is not only applicable to the diagnosis of being HIV positive, but also important in terms with a person's beliefs regarding antiretroviral therapy and the need to utilize it in order to maintain health.

“... it's part of your life ... it needs to be done ...”

“You need to come to a point where you know this is who and what I am ... you need some resilience to overcome underlying issues and to face reality.”

“... it is important to get over the barrier of medication before you start ...”

Accepting these major life adjustments took different participants varying periods of time. In a report by the National Institute of Allergy and Infectious Diseases, health-care workers report that patients often take months to accept their HIV diagnosis and to return for treatment. Subsequently a huge disparity exists between the number of patients who tested HIV positive and the number of patients who enrolled for treatment (US Department of Health and Human Services, May 2004; US Department of Health and Human Services, July 2005).

Some participants indicated that acceptance was something they needed to work on. It did not come easy and for some it took time to arrive at this point. Participants who knew from the start that they needed to accept their treatment in order to optimize adherence, might have been in a more privileged position than those who started treatment during a phase of emotional turmoil, ending in inadequate adherence.

“... for me it was like having a conversation with myself. It's a huge step to know that you have to do this for the rest of your life. So it does need a bit of thinking through and for making that leap ...”

“I didn't take my medication the following day ... I was making a conscious decision that I mustn't start taking this the following day because as I said I hadn't established a routine ... going away, and it doesn't help me to establish a routine. So then, the jelly bean thing I think will help ... so you can practice ... enough time to establish a rhythm ... without being too afraid of making a mistake ...”

Healthcare providers should consider that at the time patients need to commence treatment, they might not have been emotionally prepared for the adjustment expected of them. Special guidance, and even intensive counselling where necessary should be offered to facilitate this transition. Hoffmann *et al.* (2005:263) suggest that patients

need to receive adequate information regarding what to expect from antiretroviral therapy to improve their acceptance of, and adherence to treatment. Adequate information may prevent patients from stopping treatment unnecessarily. Healthcare providers should, however, guard against information overload as it may frighten patients (Population Council, Horizons Program, Kenya, 2004:45, 106).

The doctor explained to you why you should start on treatment, but you still had to come to terms with it yourself ...

"I started 2002 ... the first days was difficult ... I think it's psychological. Because they tell you to take, remember to take your medications. It's drummed into you, and at times you forget ..."

Entertaining a vision of the future and the milestones still to be accomplished was a main theme expressed by most participants. Although it may indicate a level of acceptance, it also is an indication of hope. Hope is an essential facilitator in the ability of patients to adjust to serious life events (*See 3.7.1.1*).

"I want to live 10 years more."

"I'm going to go with the company I just opened. I'm going to talk, do things, I'm not going to sit here and cry ..."

"I don't think it's time for me to die now. Not today ..."

"I'm not ready to die. I'm enjoying myself."

"Still five or ten years, and after ten years I'll be gone ..."

"I don't have a sort of clock, that say, oh you might not reach 50, you might not get there. I'm not scared of death. I must go on with my life as if there is nothing ..."

"... look at the future in a positive way ... I've never lived negatively, ever since. It's only in 1997, because I was like 'what?!'"

These statements imply that failure to attain acceptance may lead to inadequate adherence or even failure to commence treatment.

"... you need to grow into the whole issue of being HIV positive and needing to go onto treatment. You get used to it in time ..."

“But I must confess the first few months it was very hard for me. I mean it was very hard to accept that for the rest of my life I'm going to be on therapy. Because generally speaking I'm not a sickly person.”

Some participants were shocked by their diagnosis. Advice to commence treatment with antiretroviral drugs also brought forward unexpected and uncomfortable emotions for some participants. Subsequently, some commenced treatment without knowing exactly what was going on. Health care professionals must be cautious not to rush a patient onto treatment, but to allow enough time for the patient to become accustomed to the idea of being HIV positive and adjusting to life-long treatment. Sometimes patients only came to a doctor for HIV testing when their CD4 cell count is already very low. This means that the patient needs to adjust to two major life crises at once.

“I did not expect it. And he said he must put me on treatment. I didn't even understand, you know, why do I have to be put on treatment ... it happened only when what happened?”

At the time when the treatment was prescribed, you didn't feel sick, but you still had questions like: Do I have full blown AIDS?; Am I dying?; Is this the end of the road?

Some participants felt that going onto treatment is a sign that they are getting sicker and may die in the near future. Health care providers should specifically address these issues of fear and death.

Going onto treatment is like choosing between death and fear.

“(Was it a shock for you ... when he said you must start on treatment? Because you were fine for a long time?) ... ja, it took me three months to start that medication ... the medication was ordered, it was there, lying there, I couldn't take the medication ...”

“... it's shocking when you go onto treatment, but after some time, now it's fine ...”

The idea of starting treatment unleashed an inner turmoil. You were apprehensive that starting on treatment might mean that you are dying. You had to come to terms with the diagnosis again. You also experience self pity and had to accept that all this is a reality.

According to another participant, you not only need to accept the diagnosis and the treatment, but you also need to believe that the treatment will help otherwise it is a

waste of time and money. Roberts and Mann (Durante *et al.* 2003:113) found that patients who did not believe in the efficacy of antiretroviral therapy, displayed poorer adherence.

“... and if you are now, your mindset is also believing that it's not going to help then agh ...”

“... it becomes psychological, why do you take them? ... I see them as a way of managing the disease ...”

“I think for the medication to work, I also need to convince myself this is what they said, it's going to be like that. Rather than being stubborn and say, ah-ah, I need my Zerit ... I have to believe this, this is no longer working, so this is going to work.”

But this attachment to a certain regimen can cause distress when a person needs to change from one regimen to another due to probable resistance.

“... once it enters into your mind that these medication is suppose to do this, x, y, z for, and you believe it, then that condition will help strengthen your resolve ... so if you then become resistant, if the resistance build up, then I would consider that ... to be of concern ...”

One participant specifically indicated that by accepting her diagnosis and the fact that she needs to be on antiretroviral therapy, brought her closer to other people who are HIV positive. This may have a positive effect on seeking information and support from other people.

“... closer to people ...”

“I knew my status and I felt closer to them (other HIV positive people) ...”

Acceptance often led to a positive and hopeful attitude towards life and being HIV positive. The importance of hope is discussed under 3.7.1.1

“I never found myself depressed and ... thinking I was going to die tomorrow. You know all this trauma with this ... you undergo, I was just like ... that time, so I just think there was no signs of TB or sick.”

“... not that I was feeling down or anything, I'm going to die now, what must I do. I haven't reached that stage ...”

You never became depressed about the HIV or the treatment ... you sometimes become depressed over other issues like work and your social life.

“(Do you think that a positive mind can do a lot to keep you healthy?) Exactly, exactly”

“... live a positive life. Have a positive mind frame ...”

“... myself I live positively ... I'm not negative about it, I do have fears ...”

“I'm not going to brood and say I'm dying.”

“... it's a sickness like any other ...”

“I can live with the disease.”

“... you have to put your mind ... you have to forget. You have to got a reason to do it. You know, you can't just give up. And I felt, I don't want to regret tomorrow ...”

“This thing is all up here (*pointing at her head*) ... I think it's the attitude ... the power of the mind is strong ... I treat this disease is just like cancer, just like TB ...”

“I think it doesn't exist in me ...”

Accepting HIV as a diagnosis and accepting the importance of treatment entails some responsibility. Burdge, Money, Forbes, Walmsley, Smaill, Boucher, Samson, Steben and the Canadian HIV Trails Networking Group on Vertical HIV Transmission (2003:[4]), stressed that information regarding antiretroviral therapy should be given to women in a non-coercive way. The option to utilize antiretroviral therapy is still the responsibility of the woman.

... “every patient must understand his/her end of the bargain ... treatment is a lifestyle adjustment. After time you start to take it for granted. You need to adjust to these changes if you want to adhere to your treatment ...”

“I also need to do my part and be cautious ... you feel patients are quick to blame the doctor when something goes wrong, but in the meantime they don't do what he/she said ... a person should be willing to do whatever it takes to achieve 100% adherence.”

“... since it's a contagious disease, and I'm aware that I don't have the kind of resistance other people have, I called him ...”

“... my system is ... not as healthy as the next person ... so I always have to be very cautious. Very careful of how I conduct myself ...”

“I really hate tablets.”



“Sometimes you still need to psyche yourself up because you still experience feelings like resentment, that an external source is controlling your life. This takes away some of your freedom and sometimes you pity yourself ...”

“Although, at the end of it all, you need to be grown-up about it and you take control again. It needs to be done, and it will be done ... counselling and special care during this time can be very helpful.”

“I told myself that this is what I have to do. To such an extent that I don't worry about it anymore. But I must confess the first few months it was very hard for me. I mean it was very hard to accept that for the rest of my life I'm going to be on therapy. Because generally speaking I'm not a sickly person.”

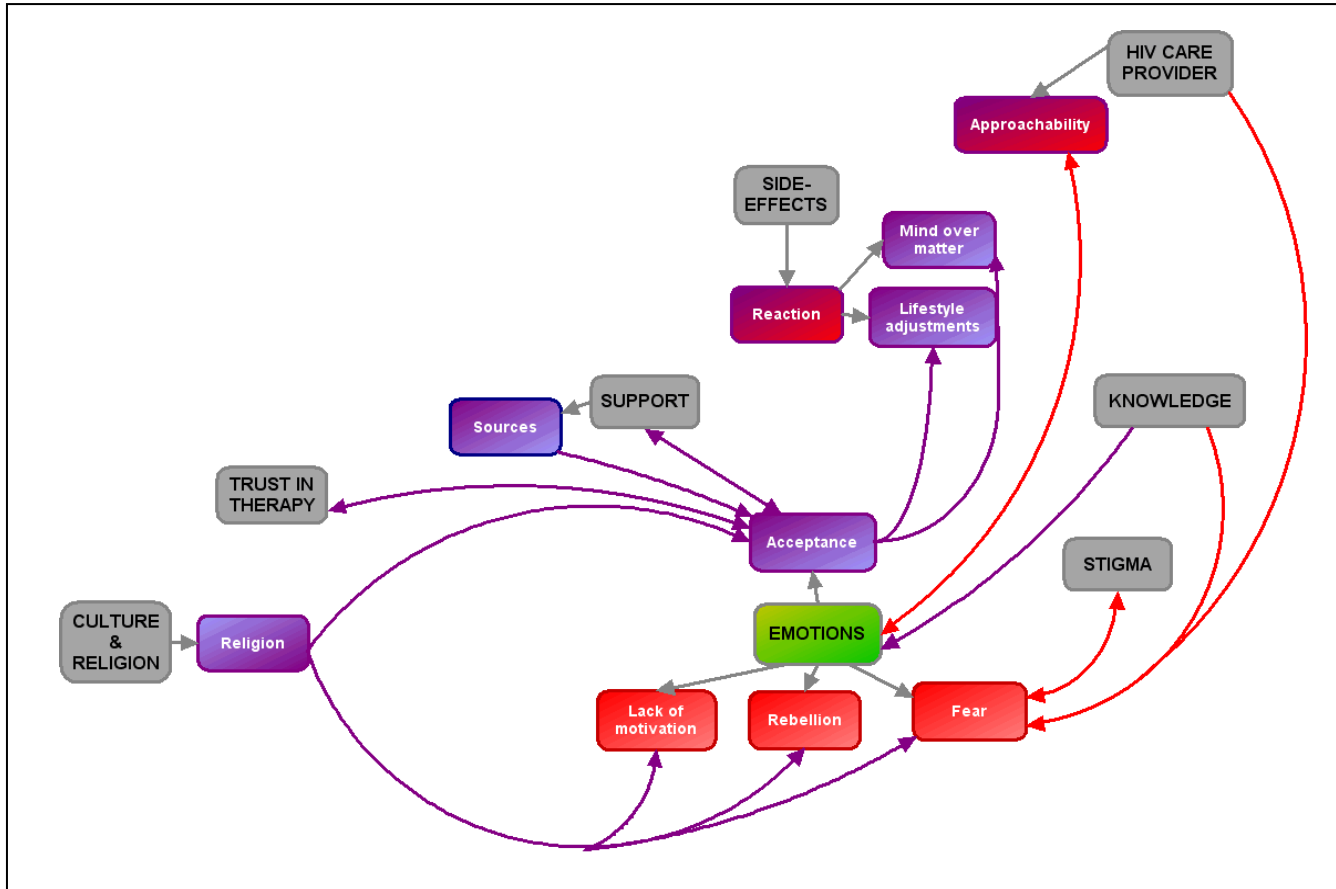


Figure 3.2.2 Aspects of emotions as it influenced or might influence adherence in context

3.7.3 Cost of antiretroviral therapy

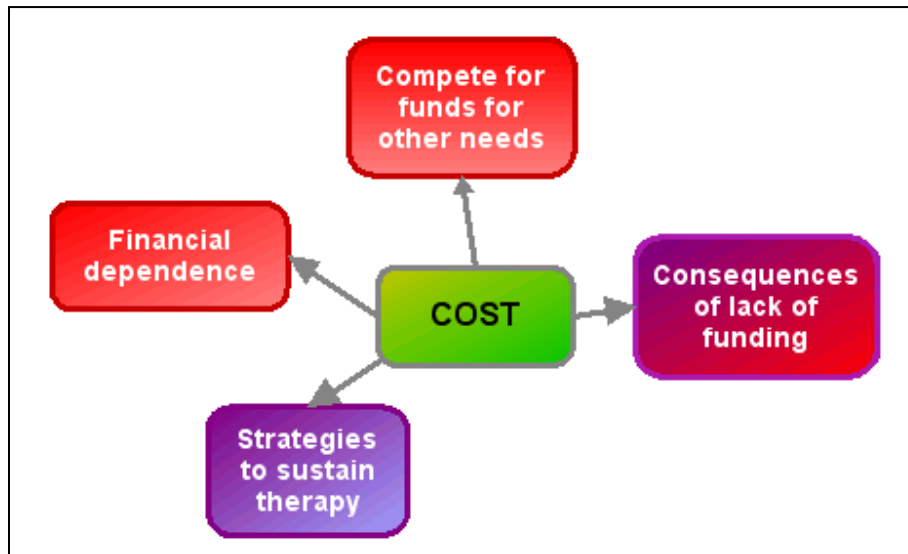


Figure 3.3.1 Aspects of cost as it influenced or might influence adherence

Financial related factors that may interfere or had interfered with adherence, according to their own experiences, observations and assumptions were discussed by several participants.

Participants came from different financial backgrounds where some were more able to contribute financially to their own treatment than others. Some indicated that the treatment was expensive and that they would not be able to continue treatment if it were not paid for by their respective medical aids. Others though, were financially secure enough to pay for their treatment exclusively from their own funds.

Paterson *et al.* (2000:26) concluded in their study that a higher monthly income is not positively associated with greater adherence. This statement may, however, have its limits under conditions where the monthly income is inadequate to provide even for basic needs like food and housing. In the majority of Africa, where this is the case, the cost of antiretroviral therapy may adversely influence sustained adherence.

In a study conducted in Botswana among people receiving antiretroviral therapy at three private clinics, researchers found that finance played a large role in the ability of a patient to adhere to antiretroviral therapy. Finances were considered to be problematic by 70% of patients while 44% indicated that the cost of the antiretroviral drugs directly interfered with adherence. The overall economic situation of 50% of the patients interfered with adherence. Another important point raised by this research is that not only the cost of the antiretroviral drugs, but also other medical expenses, lack of food and a lack of money for family needs, were considered to be a burden (Weiser *et al.* 2003: 284).

“I can’t afford those medications because this treatment is for my whole life ... and the medication is too expensive.”

Dr Orrell of the Diana, Princess of Wales HIV Research Unit at Somerset Hospital, Cape Town, South Africa acknowledges in a report that issues regarding finance can prove to be a significant problem in adherence to antiretroviral therapy (Poppa, 2002).

Several studies on adherence to antiretroviral therapy conducted in Africa support this statement. In a Senegal study, researchers found that in the time period 1999 - 2000, participants who were required to make a financial contribution, 50% attributed inadequate adherence to financial difficulty. Compared to the following year when antiretroviral therapy was issued free of charge, only 15% of inadequate adherence were due to financial difficulty (Alcorn, 2004).

A small study in Nigeria which followed adherence in 53 patients also supported this trend. Although the findings in this study were not statistically significant, the most frequently reported reason for inadequate adherence was the inability to afford medication (Alcorn, 2004).

According to the “Free by 5” Campaign for Universal, Free Antiretroviral Therapy, patients who have access to free treatment were more likely to seek healthcare and consequently display better adherence (Whiteside & Lee, 2005).

3.7.3.1 Financial dependence

In many South African cultures a woman is subordinate to her husband. Where this is the case she has little or no say regarding financial and social matters. As the head of the household the husband is responsible for the wellbeing of the family (See 3.7.1.3).

“... if you are not working, you don't have any income or what, you just listen to the boss, the boss is the husband. Because they are the ones who are making the money. Without them you won't survive. So they just listen to them ... I think the problem can be when it's about money ...”

If for some reason he considers antiretroviral therapy of lesser importance than other family needs, it may be very difficult, or even impossible for her to obtain and adhere to antiretroviral therapy. Although the South African government supplies antiretroviral treatment at some accredited facilities, these facilities are still too few in comparison with the vastness of the country and the lack of reliable transport facilities. Although HIV positive people may obtain medication free of charge, they still need to pay for transport to collect their medication, undergo laboratory testing and attend follow-up consultations with doctors at these facilities. In circumstances where a financial contribution is needed patients may altogether have no access to treatment.

One study determined that adherence to tuberculosis preventative treatment for HIV positive patients could be significantly impacted by a lack of control over economic resources. People who are reliant on their parents or husbands for financial support, including women, are especially vulnerable. Ongoing competition between the needs of the family and the needs of the individual when it comes to medical care and prolonged treatment, also plays a role (Rowe *et al.* 2005:265).

However, some participants indicated that this phenomenon is gradually changing and more women now have a say in financial and social matters. This may be the consequence of more women being educated beyond school level and consequently earning their own income.

“But it depends, things are changing, you know, some men are different.”

“... sometimes if you are independent and you are able to work, your own salary, maybe you can at least have a say. But if she is not working and the man is the ...”

Although the cultural beliefs about the status of women in society may hamper women from accessing antiretroviral therapy, two participants indicated that their husbands treated them differently. They supported them financially as well as emotionally, even though one’s husband could not commence treatment himself due to a lack of financial means.

“... my husband helps me ...”

All the participants in this study were earning an income ranging from R19 212 to more than R204 801 per annum. High end earners were more likely to display independence regarding their treatment and associated decisions than low end earners. Low end earners were dependent on another person, mostly their partner or husband, or a financial benefit, to help them sustain therapy.

“Financial independence can play a part in a woman’s adherence.”

“I actually pay for myself.”

“... you are fortunate if you are able to pay for yourself ...”

One participant indicated that she wanted to change employment but her first concern is regarding the medical aid benefit of the potential new employer. She did not want to compromise her current benefit as it aided her adherence to antiretroviral therapy.

“Because sometimes when I’m looking for a new job, I always ask, what kind of a medical aid you have. That’s the only thing, when I’m looking to move from ... the one thing I make sure that’s available is the medical aid.”

The cost of antiretroviral drugs is not the only problem. In order to sustain adherence, the patient needs to do laboratory tests for toxicity and efficacy monitoring between three to six monthly. When commencing treatment these tests may even be more frequent. A patient also needs to visit the doctor three to six monthly to interpret the test results, to check for possible opportunistic infections and to decide whether treatment should be continued or changed. According to “Free by 5” Campaign for Universal, Free Antiretroviral Therapy, the cost of laboratory tests can deter some people from joining treatment programs (Whiteside & Lee, 2005).

Medical aids have different benefit structures for antiretroviral therapy. Payment for the medicine, the accompanying visits to the doctor and laboratory tests may come from different allowances within the fund. It may happen that a patient has enough medical aid funding for the medication, but cannot afford to do the laboratory tests or visit the doctor.

Medical aid benefits for HIV treatment and care changed considerably over the past years. More medical aids now pay for antiretroviral therapy and supportive care than was the situation several years ago. However, some medical aids’ benefits for HIV care are still limited and require the patient to make a financial contribution in order to maintain treatment. The benefit for HIV care of some medical aids is not separated from benefits for general (acute and/or chronic) medical care and some even have a pooled HIV benefit per family. This implies that a medical aid benefit for HIV care can be exhausted if the funds are distributed to another family member or other medical emergencies and illnesses. Patients are not always knowledgeable about the benefit structure of their medical aid, and may be surprised when trying to collect medication, that their funds are exhausted. Accessing emergency funds are not an option for many patients.

Most medical aids in South Africa require their members to register on an HIV management program in order to access funds for HIV care. If a member does not register on this program, only general health care funding are available causing funds to be exhausted by HIV treatment before a financial year had expired.

One participant was not aware that she needed to register on the HIV management program and subsequently paid for her antiretroviral therapy mostly from her own funds and partly through her medical aid.

“... (*the medical aid pays for*) medication, and not all ... I spent R900, R950 ... that medication is too much ...”

“... my medical doesn't pay for HIV, so before they pay for HIV I must register there ... I even didn't know ...”

She interrupted treatment due to financial difficulty. After registering on her medical aid's HIV management program, she needed to make no financial contribution and she was more satisfied with the situation.

“I speak to her, and then he made a connection with my medical aid. So that problem is solved. Now I don't even pay a cent for those two months”

This particular participant's experience should urge health care professionals to ensure that their patients are knowledgeable about their specific medical aid's requirements and benefits. Insufficient benefits could be supplemented by savings or the patient's treatment plan could be tailored to match the available funding. For example, less expensive drug options and generic equivalents could be utilized where the medical aid benefit for medication is limited. However, if the medical aid benefit for medication is sufficient, but the benefit for doctor consultations or laboratory testing is limited, it may make more sense to put the patient on a regime that is known to cause little side-effects and toxicity.

During the hospitalization of one participant's husband, their medical aid refused to pay the hospital bill. The specific hospital initiated legal action against the participant for the outstanding money. Ever since this incident, this participant distrusted their medical aid and would rather pay for her antiretroviral therapy herself than run the risk of this unfortunate incident recurring. Patients, who utilize the services of a pharmacy delivery system, need to make a payment in advance to receive their medication each month. Late payment by the medical aid could mean that medication will not be delivered on time and that can lead to temporary interruption of treatment.

"... my medical aid is just that you can go on the phone and you can ask for this, and you can be sent from pillar to post and you can be put on hold until you put the phone down ..."

"I pay for myself ... I think it was just that experience ... (*medical aid didn't pay previous hospital bills*)"

Several participants indicated that unplanned healthcare expenses were both financially and emotionally difficult.

"... sometimes I became so negative for the medication I had to pay from my own pocket ..."

"... sometimes when I'm sick I have to pay from my own so that I can keep this one for the blood tests ... it was like strenuous to me, financially ... it was a shock because I had to pay everything ..."

"... one thing that I think that can make things difficult is when the funds are exhausted ..."

3.7.3.2 Strategies to sustain antiretroviral therapy

Participants in this study expressed a positive attitude towards adherence. Even in the light of financial difficulties most said that their adherence would not be affected adversely.

"Financial difficulties will not influence adherence."

"Paying for treatment and medication from own funds will not influence adherence ..."¹

However, some expressed concern that the need to save money in order to buy medication, pay for blood tests and doctor's visits may have a negative impact on their adherence.

It will be difficult to save if need to pay for medication, bloods tests or consultations from own funds. It might therefore influence adherence

In the light of the importance of antiretroviral therapy, most participants considered it worthwhile to make a plan to overcome financial difficulties.

"I wasn't prepared but I said, because it's for my health, I'm ready to make a plan."

"... because it was my health, I had to save the money every month so that maybe in December when I see I don't have money, I can take that money and then pay ..."

"... some of the times they are late to make their payments and then I'm making those payments."

"I make some payment ... I don't have any problem ... no I don't worry, I just care for my life ..."

In order to sustain uninterrupted therapy participants employed different strategies. One participant negotiated with the pharmacy to supply her with enough medication for one day so she could borrow money to collect the rest. She was prepared to fight for what she considered to be important.

"I've told you, I couldn't get my medication for this month in time ... I had to fight those guys ... you tell me I must go home without medication, give me one tablet ... give me two tablets, one for the evening and one for the morning, then tomorrow I will come. I'll get money somewhere ... it's hard to negotiate with these people anyway. You go there they want their money there and then."

A family member of one of the participants had to buy his own antiretroviral drugs for lack of a medical aid. As the drugs are expensive, he tended to reduce the prescribed dose in order to make the medication last for longer.

Sometimes participants needed to make sacrifices not to interrupt their treatment. Seven of all the participants in this study were also mothers. This implied that they also had caretaking responsibilities towards their children and that from time to time

the needs of the family took priority above their own. Fortunately, prior to and for the duration of the data collection, no participant needed to sacrifice her antiretroviral therapy for the needs of the family. However, the possibility still exists.

“I used to take them (*vitamins*) but now with this financial constraint thing, it’s difficult to just go buy medication. I had to make sure I pay school fees, I had to make sure my kids, you know, they have food in the house. Ja, and these things they are expensive ...”

“Paying partly for self ... it’s difficult to make co-payments, have to compromise ...”

Financial difficulties caused by late or non-payment on the part of the medical aid, or problems with medication delivery were solved by contacting the responsible service provider.

“I phoned her, and then she was checking the system and she found the mistake so she rectified all ...”

“... she give me hers, so I’ll phone on Monday.”

Sadly, but not uncommon, is self-imposed treatment interruption due to insufficient funds to obtain antiretroviral drugs.

“... those two months, I’ve got a problem of finance, that’s when they didn’t deliver my medication ...”

One of the participants who reverted to this action expressed severe anxiety regarding the possible implications of interrupting her treatment.

“I’m scared. I don’t know what’s going to happen ...”

Sporadic access to sufficient money or insurance to maintain treatment may lead to poor adherence if a patient is not able to utilize other resources. This implicates also poor adherence to doctor’s visits and leads to insufficient monitoring of antiretroviral therapy. As inadequate adherence is associated with insufficient virus suppression, intermittent drug therapy as a result of financial constraints may speed up the

development of resistance (Livesley & Morris, 2004:581).

3.7.3.3 Consequences of insufficient funding for antiretroviral therapy

Although none of the participants interviewed reverted to alternative or traditional medicine due to a lack of funds or difficulty accessing antiretroviral therapy through the government healthcare facilities, many said those may be reasons why many HIV positive people revert to alternative or traditional medicine (*See 3.7.1.2*).

“... no money and no medical aid ... it's the end of the road. They have no option ...”

“I think maybe it's frustration, they don't have medical aid and money like before ...”

“... ja, they would, and the reason why they would is because it would still be and option, it would still be something to hang onto. And it would be the fear of dying more than anything that would drive them to ... let me try this ...”

Most participants expressed their reluctance to access free antiretroviral therapy through government healthcare facilities. Although many could not supply a legitimate reason why they felt that way, they said that they would rather stay without treatment than go to a government facility. One of the participants imagined it would take a lot of time to get medication from the government facility. Her assumption might have been based on the long waiting periods patients usually endure when visiting these facilities.

“... sometimes it takes time to get the ARV's from the government hospitals ...”

During a conference in April 2005, co-hosted by the health department of the University of the Free State (South Africa), health care professionals shared their experiences regarding the government funded antiretroviral program. One of the main concerns was the delays encountered during the second half of last year due to a drug shortage. This incident might have played a role in the death of 95 patients. Many

patients accessed treatment for the first time when their immune status has already been severely compromised. These patients could not afford to wait for treatment (Cullinan, 2005).

Other participants felt that the treatment they would receive at government facilities from the health care personnel, would be unpleasant. One participant received her HIV results at such a facility and reported that she had to ask personnel who were not directly involved in her care to leave the room in order for the doctor to give her the results. She experienced them to be nosy and discussing things behind her back.

“... especially if you go to the black nurses, you find even ... you can see the way they treated you, then you see the other ones coming, like they've been talking ... you'll see the other one popping in ...”

Another participant witnessed the rude treatment of patients at one of the government facilities. In this instance a nurse disregarded all principles of patient confidentiality, trust and respect.

“A nurse at one of the government facilities was rude to some young people. She shouted at them. She discussed their HIV results in the waiting area where everybody could hear ...”

“I wish I can bring treatment to the people who can get their treatment closer to them. Because this other system is not pure. You cannot go to clinics now ...”

3.7.3.4 Implementation of the Medicines Amendment Act No 89 of 2004 by the South African Government

The South African Government passed the Medicines Amendment Act No 89 of 2004 in August 2004. According to the amendment, pharmacies are allowed to charge a dispensing fee of 26% of the single exit price up to a maximum of R26 for each drug prescribed. Before, pharmacists put a mark-up on medication before selling it to the public (Treatment Action Campaign (TAC), 2004).

As the mark-up was incorporated in the medication price, it was usually paid for by the medical aid. Some medical aids however, required from their members to pay for the dispensing fee themselves. This implied that although the overall price of medication was stabilized, and even less than previously charged, some patients actually paid more for their medication themselves.

“... when you have the medical aid, you think you are protected. And all of a sudden you have the medical aid, it goes through, but then before they give you the medication, then they tell you the system has changed ...”

“... now every month I have to pay, because my budget is now, is now minus 300 ...”

At the time of constructing this research report, a court verdict regarding the implementation of this act was still outstanding. This verdict might necessitate amendments to the current act.

In the words of Zackie Achmat (Achmat, 2004:14):

‘HIV/AIDS establishes a new apartheid. The new apartheid exists between those who can buy health and life and those who die because they are poor.’

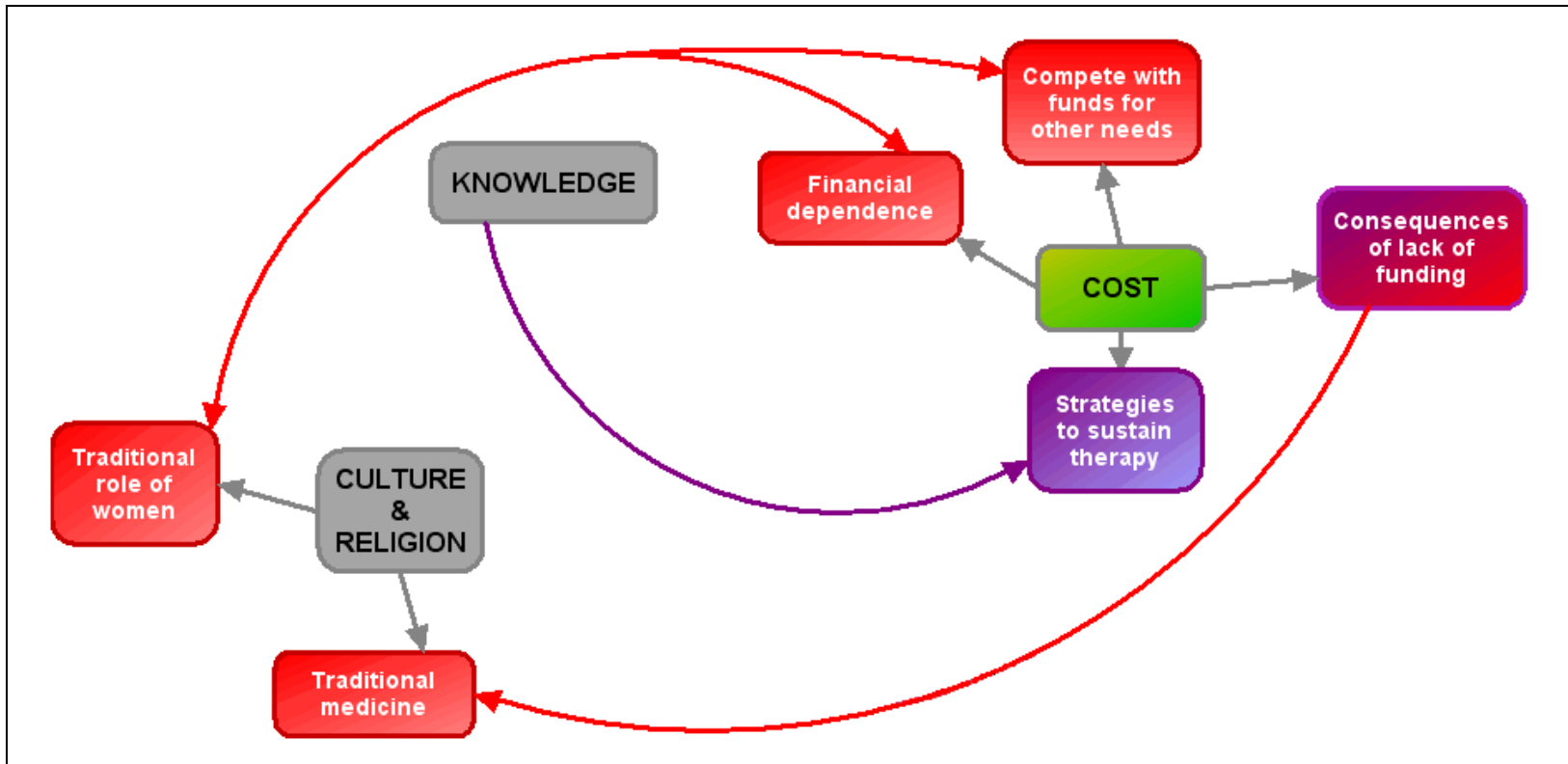


Figure 3.3.2 Aspects of cost as it influenced or might influence adherence in context

3.7.4 Side-effects of antiretroviral drugs

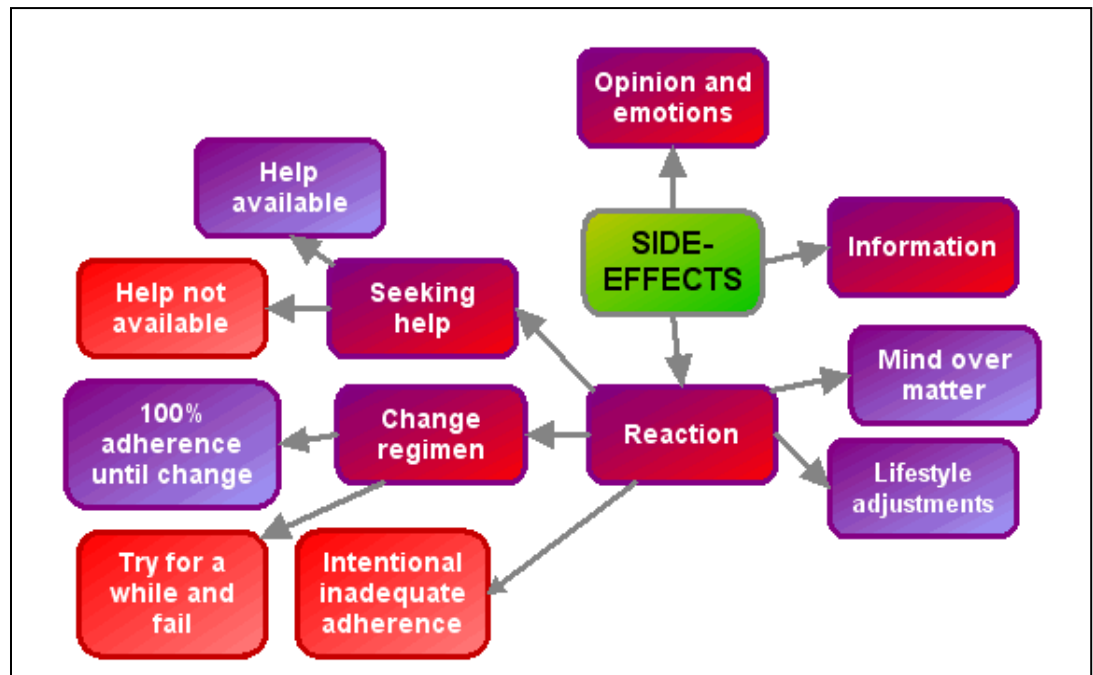


Figure 3.4.1 Aspects of side-effects as it influenced or might influence adherence

3.7.4.1 Managing side-effects

A cross-sectional multicentre study within the Italian Cohort Naive Antiretrovirals (ICONA) found that inadequate adherence to antiretroviral therapy was significantly associated with reported symptoms and side-effects. This is of concern if taken into account that antiretroviral therapy is prescribed for life and HIV positive people will thus be continually exposed to antiretroviral drugs and its side-effects (Ammassari, Murri, Pezzotti, Trotta, Ravasio, De Longis, Caputo, Narciso, Pauluzzi, Carosi, Nappa, Piano, Izzo, Lichtner, Rezza, Monforte, Ippolito, Moroni, Wu, Antinoro & the AdICONA Study Group, 2001:S126).

Side-effects caused intentional inadequate adherence in general in 4% to 7.4% of participants. Intentional inadequate adherence included selective skipping of medication or taking a drug holiday not recommended by their doctor. Maintaining

quality of life seems to be one of the main reasons for this action. These actions may occur regardless of a symptom's strict clinical importance and health care professionals should therefore be sensitive towards a patient's perception of side-effects (Heath, Singer, O'Shaughnessy, Montaner & Hogg, 2002:[5]).

Women are more prone to severe side-effects and toxic manifestations than men. For example, lactic acidosis and hepatomegaly are more commonly found in women than in men. Irrespective of protease inhibitor use, fat re-distribution resulting in an increased breast and waist circumference, are also more common in women than men (Squires, 2003:[5]).

One participant experienced severe side-effects since starting a new antiretroviral drug. She decided to reduce the dose rather than stopping it. Before implementing her decision, she discussed her decision with her pharmacist, who advised her to consult her doctor on the issue. She, however, did not consult the doctor and reduced her dose. The dose reduction did not lessen the side-effects and eventually she asked the doctor to change her medication to something else.

"I was suppose to take three at night, and then I couldn't take three, it was too much for me. So I only took two ..."

"I decided to reduce the dosage rather than leaving it. Because I read in the pamphlet that you shouldn't stop it. So I thought stopping it is going to aggravate me ... So I decided rather than leaving it completely, I will take two, just to reduce the dosage ... three months, it was, the first month I took three ... but I struggled with the treatment, it was not nice. Taking it everyday, but I thought maybe after two months I'll be fine. I went back there the third month, it was still like that, and I decided, uh-uh, rather change this."

Her doctor changed the drug causing the side-effects to something else, to which she experienced even worse side-effects.

"... the rash was red, I was scary ... also gave you a rash ... this time it was different ..."

She tried to consult her doctor, but he was not available at the time. On his telephonic recommendation she consulted her general practitioner who advised her to discontinue the treatment.

“... and then the doctor was not around and I went to another doctor and the said stop it immediately. Because I also don't understand these things, but if this leaflet says if there's a rash, stop, then I say stop it ...”

“I stayed without treatment ...”

Another participant also experienced severe nausea after taking her medication and decided not to take it.

“... usually it happens at night, then I felt, I want to throw up ... I say ah, today I won't take the second tablet ...”

Most participants in this study however tried to manage their side-effects in a positive way as to avoid treatment interruption.

One participant explained that when she experienced side-effects, she would take something to relieve the symptoms.

“... drinking tablets sometimes, my stomach is sometimes just full of air. Then I maybe have to take something to relief that ...”

According to Weiser *et al.* (2003:285) 51% of the participants reported side-effects to antiretroviral therapy but only 9% of those consider side-effects to be interruptive of antiretroviral therapy.

Health-care professionals are more prone than patients, to think that side-effects are a major barrier to adherence of antiretroviral therapy. Due to the severity of HIV as a disease, and the implications of poor adherence, patients may be more tolerant toward side-effects than generally expected (Gallant & Block, 1998:34).

“(Does it make you feel not to drink your medication?) ... Ah-ah, No”

“Did that ever make you feel not to drink the medication?” ... No”

3.7.4.1.1 Mind over matter

The same participant who stated that she did not take her medication at night because of the severe nausea that it caused, decided later on that taking the medication is important and that she need to do it in spite of the side-effects.

“... usually it happens at night, then I felt, I want to throw up ... I say ah, today I won't take the second tablet. The last ... the evening one. But now, I don't care. Even if I feel, I think I only done it once. That other time I felt everything was here. And the next time I felt like that I said, you know what, I don't care, if I throw up, then it will be, but I'm taking this one ...”

3.7.4.1.2 Lifestyle adjustments

Taking antiretroviral medication without eating something first, caused diarrhoea in one participant. As she was not used to eat early in the morning she had to spend some time discovering how much she can tolerate eating at that time of day, and what amount of food will prevent the side-effects. She changed her habits to accommodate the treatment requirements. From time to time this participant had to force herself to stick to these requirements.

“... if you take the tablets on an empty stomach, you get a runny tummy ... if you eat something but it's too small, you ... you end up as a runny tummy. So that's how I discovered my portions ...”

“... personally I don't like eating in the morning. So I had to learn to eat a particular ...”

“... but I forced myself ...”

The nausea caused by her antiretroviral drugs, caused one participant to take her medication at 03:00 in the morning and then went back to sleep. By the time that she had to rise for work most of the side-effects had subsided.

*“I had to, even if it makes me nauseous, I had to drink it. You know what I did? When I started, I drink * at three o'clock in the morning ... I had to take it three o'clock in the morning so that I sleep*

a little bit, it dissolves and get whatever. I then wake up and have my breakfast and be able to go to work.”

Taking an alcoholic drink, or staying up after taking the evening medication, caused one participant to experience difficulty to sleep. If she managed to fall asleep, she suffered from nightmares. Consequently she decided to exclude alcoholic drinks largely from her lifestyle.

“Kind of the longer I stay awake, after I’ve taken my medication, I have difficulty in sleeping ... I don’t know if that has anything to do with the medication, or it’s in here (*pointing at her head*).”

“I will drink stuff like ... and I’m also weird, because I will dilute it with lemonade. So it’s weak, but if I just make that mistake, then I cannot sleep the whole night. I can’t sleep at all. So I’ve just disciplined myself to say I don’t do that. I can’t do it. If I sleep ... I do (it) get vicious nightmares.”

3.7.4.1.3 Request change of treatment regime

Experiencing severe and uncomfortable side-effects that did not subside after a few weeks on treatment caused several participants to request a change of treatment from their respective doctors.

Participants in a study conducted by Adamian, Golin, Shain and DeVellis (2004:235) identified factors that will improve their adherence to antiretroviral therapy. One of these factors was improved communication with their health care providers and admitting when they experience difficulty with adherence due to a specific regimen.

“I was using the *⁴ and then I said I don’t want * anymore because I was like, I was not right ... then we changed this med ...”

“I was using * and *, and I asked the doctor to change me from *, because it was making me feel very nauseas. I think the dose was just too much, because it was three in the morning and three in the evening ...”

“... as I also asked the doctor to change me from it, because sometimes it will make me feel so nausea ... sometimes I couldn’t even take my vitamins, because I’m just too nauseas ...”

⁴ Drug names removed for reasons of confidentiality

“... only when you react on the medication you might consider changing that medication to something else ...”

3.7.4.1.4 Seeking help

Most participants indicated that they would consult their doctor if any symptoms out of the ordinary were to emerge. Expected side-effects that persist for a prolonged period of time and side-effects that cleared up, but re-appeared after some time, would motivate participants to contact the doctor.

Patients at large look at HIV specialists for information regarding antiretroviral therapy and its potential side-effects. In a study conducted by Gellaitry, Cooper, Davis, Fisher, Leake Date and Horne (2005:373), did 75% of participants accessed information regarding antiretroviral therapy through the doctor, 70% through the pharmacist and 51% through the hospital nurse.

“... if it happen again, before two weeks, I'll phone (*the doctor*) ...”

“I'll go to the doctor ... I'll wait for two days, and then ... to see if that thing continuous. And if it continuous, I'll go to the doctor ...”

“... if you drink any medication and you then have a prolonged runny stomach problem, it actually comes out of your system, because it doesn't stay in as it is suppose to ... if I had diarrhea, I would phone the doctor, tell him ... then I came through and we spoke about it ...”

“... (*diarrhoea*) if the doctor tells me before, I won't have any problems but if this thing continue, I'll go to the doctor ... I would give it a week ...”

3.7.4.2 Information regarding side-effects

Most participants acquired their information regarding expected side-effects from their doctors. A few preferred to read the enclosed medication pamphlet which also list all the possible side-effects of the specific drug.

Patients should be informed of potential side-effects and how to manage it as it may

lead to better adherence (Ammassari, Trotta, Muri, Castelli, Narciso, Noto, Vecchiet, Monforte, Wu, Antinori & the AdICONA Study Group, 2002:S125).

“... when I go to a doctor, I expect him ... also alert me of the side-effects ...”

In one study highly treatment experienced patients were asked to evaluate different treatment regimens' influence on adherence. They considered pill count, dosing frequency and side-effects to have the greatest impact on patients' perceived ability to adhere. Side-effects and dosing frequency were considered to have an influence of 13%, with pill count 14%. The potential impact of side-effects on adherence should prompt healthcare professionals to be more pro-active in this regard. Suggested actions include:

- Discuss potential side-effects with patients
- Take preventative measures to minimize side-effects
- Manage side-effects actively when they occur

(Stone, Jordan, Tolson, Miller & Pilon, 2004:[7, 9]).

The participants in this study expressed their views regarding side-effects as follows:

“... well the doctor alert me to that ... so I am aware of that ...”

“... but for the first week it was, after taking them in I just feel dizzy, but actually it was not that bad as he told me before: For the first week maybe you will not be fine with the medication but you must just proceed ...”

“... it depends also on the information I would get when I'm getting the medication. If they tell me, look, you will expect these, you might experience this, after effects. I'm kind of prepared ... but if I haven't been informed and suddenly there's a change of ... regime, and then I'm having these after effects ... my first inclination is I will call the doctor ...”

“... if I'm forewarned, and I experience it, I think I can accept it. But also not for a long period ...”

“... they also tell you, you might expect side-effects, which I think is fair ... you are like, with antennae, looking out to see, would this be a side-effect? Any small thing you suddenly assume, it might be this ...”

"... but I'm also thinking it can be psychological, because I when is started on the *, I was informed that OK, you might find it difficult to sleep. Or it might actually make you very, very drowsy ..."

3.7.4.3 Opinions and emotions regarding side-effects

In his lecture on HIV and Human Rights, Achmat (2004:4-5, 37) gave a short history of the fight against HIV in South Africa. Prior to 1994, HIV received little attention as the government at that stage consider it to be a problem ascribed to a minority group. With the election of the new government in 1994, were HIV pushed to the background in favour of more pressing matters. This was followed by a severe debate in parliament regarding the link between HIV and AIDS, lasting way beyond the break of the new millennium. Only at the end of 2003 did the South African Government propose a comprehensive response plan to combat HIV.

This debate not only evolved around the link between HIV and AIDS, but also targeted the effectiveness and toxicity of antiretroviral therapy.

In a press conference President Mbeki said the following:

"... large volume of scientific evidence alleging that, among other things, the toxicity of this drug is such that it is in fact a danger to health."

"It would be 'irresponsible' not to heed the 'dire warnings' of researchers about the safety of AZT."

(Wakin, 1999).

Many people do not have access to informed sources to obtain information regarding antiretroviral therapy. This lead to a widespread fear towards the antiretroviral drugs.

"I mean people say it will make you sick, it will make you feel nauseas, it will make you this, it will make you that. So I needed to be psychologically prepared to fight whatever ..."

"... but with his medication. The HIV medication, no I wouldn't do it. The only side effect was that I had difficulty to sleep when I had the * (*referred to stopping diuretic for hypertension*) ..."

Although most patients experienced some side-effects, it varied in severity and duration. However, most indicated that they became accustomed to the treatment after a few weeks. Side-effects included mostly nausea and dizziness.

“... my body is getting used to it ...”

“I’m used to the medication now ...”

“... it felt a bit different and a little bit nauseous. But after some time I found that it went away ...”

“... no, I was just feeling dizzy. After drinking them I just feel that I can sleep for a while, for an hour ... but it only took me a week, then on the second week I was fine ...”

“... sometimes I was just feeling to vomit, but it took me only a few days. It was four days ...”

The participant who experienced severe side-effects from several different drugs, was the most negative about trying to overcome the inconvenience and discomfort.

“I just wanted to change it again ...”

Severe and prolonged side-effects caused fear in most participants. This fear was inflamed in the presence of inadequate knowledge regarding antiretroviral therapy and its anticipated side-effects.

“... the first week I’ve started ... I developed pimples ... I didn’t understand what it was all about ... I was really scared that maybe it’s a sign that I am really sick. I’m going to die ...”

“... and the dizziness in the morning ... I didn’t understand what was happening ...”

“... oh, I was very scared, on Saturday I thought I was dying ...”

“I had a rash, and then I didn’t understand what was it ... I was so worried ...”

“... it was difficult before ... especially if you get these side effects ...”

“... it’s itching and tearing ... I was too scared to drink any ... since Saturday and Sunday and today ... I couldn’t drink anything, it was terrible ...”

Participants who were warned about potential side-effects seemed to be more tolerant and usually reverted to waiting it out.

“... they made me scared more than anything else, ja, but I didn't stop because of this ...”

One participant indicated that the absence of side-effects made it easier to get used to the medication and the treatment regime.

“I actually enjoy my medication anyway, because I don't even feel it ...”

Another was more tolerant towards the side-effects that she experienced with her new treatment regime as it caused less side-effects than previous one.

“... this one, even, it was better than that one, there was no nausea, head aches. After drinking it, I could even forget that I took any drug ...”

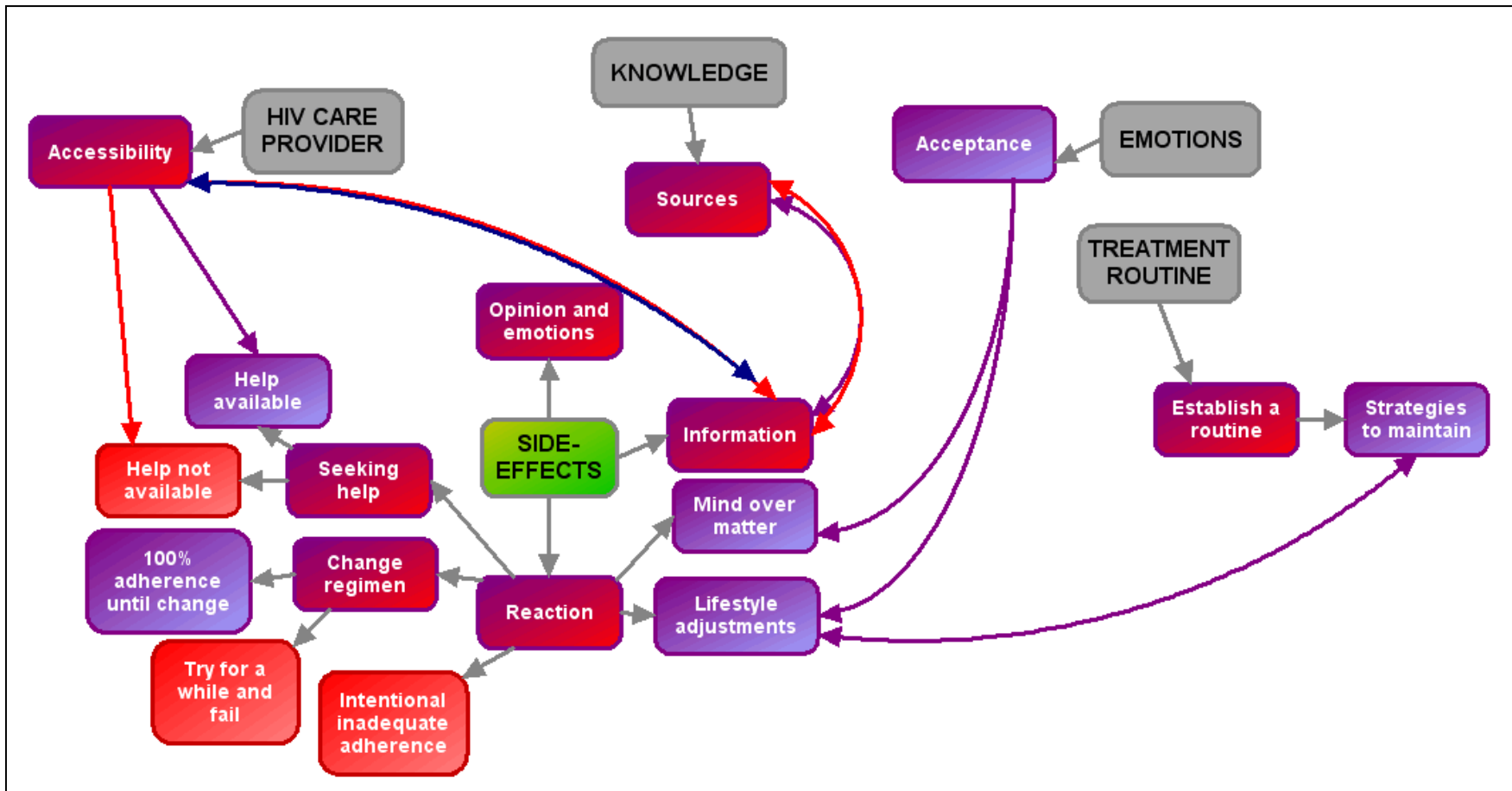


Figure 3.4.2 Aspects of side-effects as it influenced or might influence adherence in context

3.7.5 Treatment routine

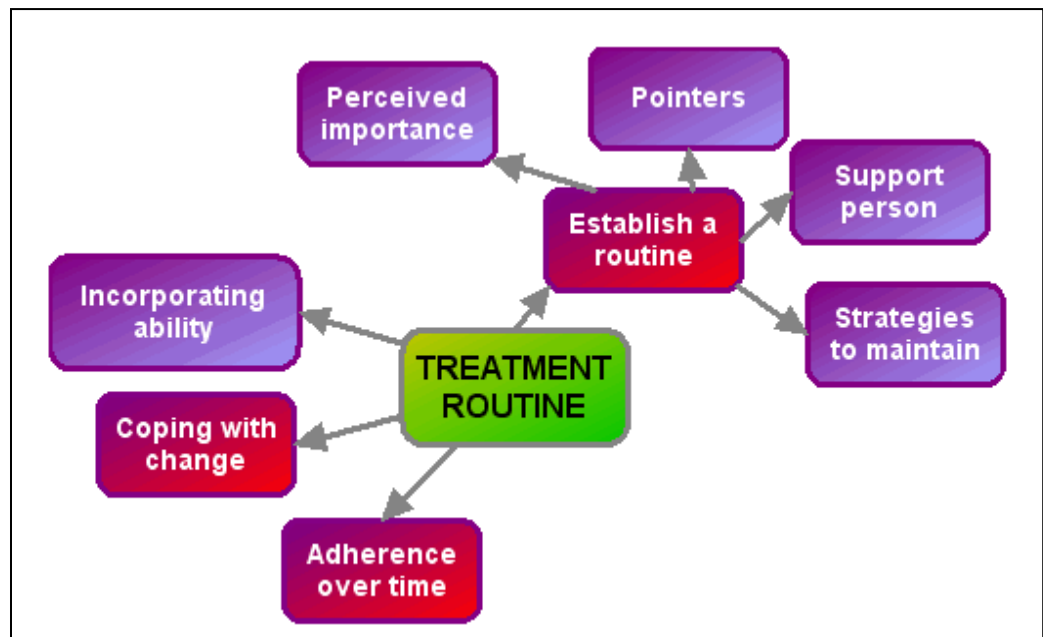


Figure 3.5.1 Aspects of treatment routine as it influenced or might influence adherence

3.7.5.1 The ability to incorporate treatment in daily routine

Most participants associated their taking medication with events in their daily routine, for instance breakfast and dinner. This strategy enabled them to integrate taking medication into their daily routine until it became one and the same event. This action had a positive effect on adherence as participants continued taking medication without even thinking about it.

“I have a system going. Most of the time I don’t even realize that I’m eating something ... I’m so used to my routine ...”

... “it’s a habit ...”

One of the critical factors in establishing and maintaining treatment adherence, is the ability to match a treatment regime with a person’s lifestyle and preferences (Rabkin & Chesney, 1998:[4]).

This important factor is often ignored by health care providers. It may be difficult for a

patient to adhere to a regimen where medication should be taken three times a day, implying that the midday dose be taken at work. If this particular patient does not have privacy at work, do not want his/her co-workers to know about the treatment and in addition have to adhere to dietary requirements, it may be difficult to adhere to this regimen. The same is also applicable where antiretroviral drugs require specific storing conditions. Some patients do not have access to refrigerating facilities, or they have to travel often. Prescribing a drug that needs to be kept in a refrigerator might compromise adherence. Health care providers need to pay special attention to a patient's lifestyle before prescribing a treatment regime.

In a literature overview of several studies, difficulty to integrate an antiretroviral treatment regime into daily routine varies from 36% to 57%. According to patients, this can be attributed to regimen complexity and dietary requirements of particular treatment regimens (Ammassari *et al.* 2002:S126).

One of the factors, identified by the National Institutes of Health (NIH), predicting adherence to antiretroviral therapy, is the ability of a patient to incorporate a medication treatment program into daily routine (NIH, 2004).

“... most of the time I'm knocking off at 10 ... when I get home (*I take my medication*) ...”

“... it's actually between seven and eight, it depends on when I have my supper ...”

“... where I put my toothbrush, in the bathroom, I used to put it there ... so what I used to do before, before I started the treatment, I used to brush my teeth, bath, go and eat and before I leave, brush my teeth again ... before I go to bed, I'd brush ...”

“I take it and then I eat breakfast at around seven ... when I eat my dinner ... like I take my pills and then my ... ja, together ...”

“... normally I take it during my tea break, like half past ten, eleven, because then I know it's my tea break. I just have my tea and then I make sure that I take it ...”

“... at night, before I sleep, I take it ... usually I'm studying until ten, half past eleven ...”

All the participants in this study took at least one of their antiretroviral drugs twice a

day. Many participants commented that it might be difficult to adjust to taking more tablets or taking medication more often. The latter was identified by most participants as a potential problem, while they foresaw less trouble adjusting to the former. Reasons for difficulty may be becoming too busy at work and subsequently forgetting to take the medication. One participant commented that taking medication more often would imply that she had to carry more medication with her and that may prove to be impractical.

“... (*you have to take a midday dose*) I think I will go out, I think so ... ja, it would be more difficult ...”

“... might be a problem. I think four times is just a bit too frequent. I have to carry a lot more stuff with me ...”

The perception that three times daily regimens induce inadequate adherence because of the midday dose, were found to be untrue by Bertholon, Rossert and Korsia (Cinti, 2000:[6]). In their study only 9% of patients considered the midday dose, in a three times daily dosing schedule, the most difficult to take, while 20% had trouble with one of the other doses.

This finding could be explained by the inconvenient timing of a three times daily dosing schedule. If a drug should be taken three times a day, in other words every eight hours, it implies that besides the midday dose, for instance at 13:00, the patient has to take the other doses very early in the morning and very late at night. In this case 05:00 in the morning and 21:00 at night. It may thus be difficult to adjust one's lifestyle to accommodate these requirements. Early risers would easily adjust to the 05:00 dose, but may have difficulty with the evening dose. If any of these doses also have specific dietary requirements, it becomes even more difficult. In other words, it's not the midday dose per sé that might be the problem, but the whole dosing schedule incorporated in a three times daily regimen. A patient who perceives an early morning or late evening dose to be problematic, may perceive slight variation in adherence during the midday dose as less important and thus not problematic.



3.7.5.2 Coping with change in a daily routine

Some participants had to cope with an ever changing daily routine due to the nature of their work. Meetings, irregular working hours and traveling are some of the interferences of a work environment that can impact on a patient's treatment routine. When a patient's medication routine is an integrated part of her daily routine, a change in daily routine can prove a unique challenge. Firstly, she can no longer rely on her routine to help her adhere, and secondly, events that may take place at the times she usually takes her medication, interfere with her adherence. She would then need to utilize other mechanisms to remember. Failing to cope with this interference, or lacking privacy to take medication, will contribute to inadequate adherence due to forgetfulness. The stigma surrounding HIV and its treatment is an ever present factor to take into consideration when it comes to adherence to antiretroviral treatment.

One participant was working shifts and had to cope with different working hours per day. Another five participants had more or less regular working hours, but traveled frequently, including overseas, or had to attend meetings and conferences that extended their working day and interfered with their working routine.

"... sometimes I go of at 6 o'clock in the afternoon ... then I'm just going to wait until its 10 o'clock ..."

In the AACTG study 66% of patients attributed inadequate adherence to forgetfulness. Among some of the reasons for inadequate adherence identified in this study were being away from home (57%) and changes in the daily routine (51%) (NIH, 2004)

Two of the participants facing this dilemma reported a rather intimate involvement with their treatment program. They explained that they are very tuned into their treatment requirements and were thus able to adhere adequately.

"I have an internal bleeper ... I went out with friends for supper, but at eight o'clock, I just went to the ladies, because by then I had eaten something, and I just drank my medication ... I watch the time quite closely."

"I noticed is that when I start going beyond the normal time, I almost like develop a headache and

I immediately know.”

A change in routine is also implied when a person goes on leave. In order to obtain data on the influence of holidays on adherence, this study was designed to run through two major South African holidays namely Christmas and Easter.

Participants reported different experiences regarding the influence of routine change on adherence. Some maintain the same routine, regardless whether they are working or on holiday.

“... go away or during the holidays ... I take it at the same ...”

However, others changed their medication routines according to their adjusted daily routines.

“I’ve changed it in December because I wasn’t waking up that early”

Most of the participants who maintained their usual medication taking routine employed other measures to help them remember. For instance one participant asked her mother to help her remember, while another set an alarm during this time.

“on leave ... oh, it will be difficult, I must make a ... maybe an alarm, to make me wake up ... I’m going to forget”

“usually on holidays, I go home, so I tell my mom, if I sleep, you must wake me up”

3.7.5.3 Establishing and maintaining a treatment routine

3.7.5.3.1 Perceived importance of a treatment routine

Establishing a treatment routine may help patients overcome the number one reason for inadequate adherence, namely forgetfulness.

Leider and Kalkut (Cinti, 2000:[7]) tested adherence among HIV negative health care workers. Only 2.85% of the participants could achieve 100% adherence. The most frequently reported reason for inadequate adherence in this study, was forgetfulness.

Population Council, International Centre for Reproductive Health Coast Province General Hospital (2004:77) acknowledges the importance of establishing a medication routine that can be integrated into a patient's daily living. They recommend that this should be part of preparing a patient for therapy and that attention should be focused on the following aspects, among others, to identify barriers and supporting factors:

- Daily routine at work
- Daily routine regarding eating and sleeping habits
- Travel routine
- Issues of confidentiality regarding antiretroviral therapy at work and home

3.7.5.3.2 Pointers to establish a treatment routine

The minority of participants reported that they immediately started with their treatment as instructed by the doctor. Some participants, however, took time to get used to the idea of lifelong treatment. They allotted some time to sit down and work out a schedule that would both match the instructions that they received from the doctor and their lifestyle.

“I just sit down and I think about it ... I consciously thought about it because the doctor explained to me ... then I just decide what would be the easiest for me ... it's more or less really understanding what I do like and what I don't like ...”

One participant emphasized that it would be unwise to rush into treatment while her normal routine was disrupted. She recommended that it would be better to wait until everything is as normal as possible.

“... it is easier, when you start on treatment, to do it from a comfortable place and circumstances ...”

3.7.5.3.3 The role of a support person

One participant indicated that her interaction with a healthcare provider helped her to improve her adherence as she wanted to make a good impression.

Coetzee *et al.* (2004:[5]) found that the relationship between a healthcare provider and a patient exerts a strong influence on adherence. A collaborative and trusting relationship between a patient and the healthcare provider leads to a sense of treatment satisfaction and increased adherence (Van Servellen *et al.* 2002:271, 275-277).

“Since the time I started seeing you, I’ve sometimes during the weekends, I was laid backed, I was very negligent, sometimes I would forget to take my medication, lying in bed and say I will take it at whatever time. But since we started meeting, I make sure that I take it on a daily basis. Because maybe, I don’t want a negative report, I don’t know, but then it helps.”

At the time of their diagnosis and commencement of therapy, two participants were very ill and were at home with their mothers. Their mothers played an important role in facilitating the establishment of a treatment routine. After their recovery these participants continued with their respective treatment routines. One of these participants mentioned that she still asks her mother to help her to remember taking her medication when she visits her during the holidays.

“You think your mom being the person who gave you the medication in the beginning ... helped you to establish a pattern.”

“... when I became better and better, I just keep on that times ... in the mornings, I used to eat breakfast firstly and after breakfast I know that I can know take the medication. The evening one ... when I go back to work, because as I said, today I knock off late, 10 o’clock, then that’s why I say I make it ten, after ten ...”

“I was sick and then I was always in bed, and my mom used to give me the first medication 10 o’clock in the morning and then about ... nine o’clock before she sleep ...”

“I was taking my meningitis (medication) ... until I came here in October.”

Unfortunately, participants may unknowingly establish an incorrect medication routine. It is important that the primary health care providers discuss this routine on a regular

basis.

“... it differs, when, say it’s today, I take it at seven o’clock, say eight o’clock in the morning, then I make sure at least at night, I take it at eight o’clock again. But the next day might changes, I might take it at half past eight, but I’ll make sure I take it at half past eight in the evening as well. So I tried not to pass different times in one day ... if the times are different, it would be maybe a few minutes ...”

3.7.5.3.4 Strategies to maintain a treatment routine

Participants utilized different mechanisms to help them to adhere to their medication schedule. One participant needed to eat before taking her medication in order to minimize side-effects. This participant indicated that she always has something on hand to eat. She also had to teach herself to eat breakfast, even though she did not like it.

“... personally I don’t like eating in the morning. So I had to learn to eat a particular portion ... have to force yourself ...”

“I always have a fruit bar in my bag ... because people don’t necessarily eat at the time that I need to eat ...”

“I must make sure that whenever I’m traveling I must have maybe a bottle of water with me so that ... usually I do have, it’s just that I was in a hurry ...”

One participant set an alarm when starting her treatment for the first time. Another had to change her treatment routine during the course of the data collection. She set an alarm for a week until she became used to the new routine.

“... but now, after I came back from the doctor, then I started setting an alarm” ...

“ ... for the past two weeks I started to set an alarm ... to notify me when it’s half past. So now I’m used to it ...”

In a web-site article, Berrien (2005) gave a few pointers regarding memory aids to enhance adherence. These include setting an alarm clocks or digital watches, putting a calendar in an obvious spot and make an X for each dose taken. This provides a quick visual tool to keep track of when the next dose is due.

Although Paterson *et al.* (2000:26) discovered that using an alarm clock to help a patient remember to take medication was not associated with 95% or greater adherence, the participant who employed this strategy experienced it to be helpful.

Keeping an extra dose or two on hand, in case of unforeseen interruptions or delays, proved to be very helpful to several participants.

"I always have a dosage in my bag ... it's always available ... I always make sure that I have an extra dosage just in case if for one reason or the other I'm not able to come back when I need to ... because it then buys me time ..."

"... when I'm in a flight I make sure that I have something. And when I have a six o'clock flight, I have my medication, my morning dose, and I drink it ..."

"... the other one is at home and the other one is at work ..."

"... it becomes part of my ... the stuff that goes into my vanity bag ..."

Many participants expressed that they learnt to cope with unforeseen events through trial and error. One participant also shared an experience where she and her husband, he is also on antiretroviral therapy, were at a social function. He forgot to take his medication along and they had to go home early because he wanted to have his medication.

"... we couldn't leave and come back so he could have his medication. So I learnt my lesson then. So I then just moved with an extra one for him ..."

"... he's getting agitated, because he doesn't have his medication so I just pass it over to him. So I also always move with back-up for him ..."

Most participants indicated that it is important to find ways to make taking medication easier.

"You must make it easy for yourself. You for instance, prepare a snack and keep it together with your tablets on your bedside table. Then when you want to sleep in a bit, you wake up, eat and take your tablets, and go back to sleep again. All this entails that a person should be willing and able to plan ahead."

... "people tend to try to cut corners after a while ..."

Getting medication on time can be tedious. Some participants traveled often and sometimes needed to obtain a medication refill at different times and places other than usual.

“... we was going to close earlier than the normal time in December, then I had to call and find out when were they going to close, and when I was away, and I then needed to make sure that I had sufficient money to pay, and at what time I actually needed to pay them. And in that way I knew OK I must make my payment at such and such a time ...”

This required a lot of planning on the side of the participant. Health care providers can help patients to find ways to make collecting medication as easy as possible. For instance, patients who usually have to collect their medication at a pharmacy, may be given the option to join a medication delivery system which will deliver their medication every month at a location of their choice. These measures can help to prevent treatment interruption due to insufficient medication supply.

“... normally I pay two days before I go and pick up my medication ...”

“... he said to me, I must phone a week before, before the delivery ...”

Planning and preparing accordingly was the golden rule one participant lived by.

“I also do a lot of planning.”

3.7.5.3.5 Adherence over time

In a study that compared the period being infected with HIV with adherence, found that patients with adherence higher than 95% were infected for a longer period of time than those displaying lesser adherence (Paterson *et al.* 2000:26).

However, other studies could not demonstrate the same association between adherence and the length of HIV infection. In general, CDC disease stage was not associated with adherence, although one study found that patients in CDC stages B or C were more likely to be adherent compared with those in stage A (Ammassari,

2002:S125).

Several participants indicated that their adherence were different from what it was when they first commenced treatment.

“... nowadays I’m on time ...”

Rowe *et al.* (2005:266) described in their study that participants, and even health care providers, find it difficult to take medication when not feeling ill. They found that many participants interrupted their treatment as soon as they felt better, and then later recommenced when symptoms emerged again. Only 8% of participants in a study conducted by Weiser *et al.* (2003:285) discontinued their treatment after their symptoms subsided. This could be attributed to strong educational efforts on the part of the health care providers involved in their care.

Although one participant started antiretroviral therapy while being ill, she soon became better and commented that it is sometimes difficult to continue with treatment when feeling well.

“... sometimes I feel like I’m OK, why should I take the medication?”

“Although, at the end of it all, you need to be grown-up about it and you take control again. It needs to be done, and it will be done ... counseling and special care during this time can be very helpful ...”

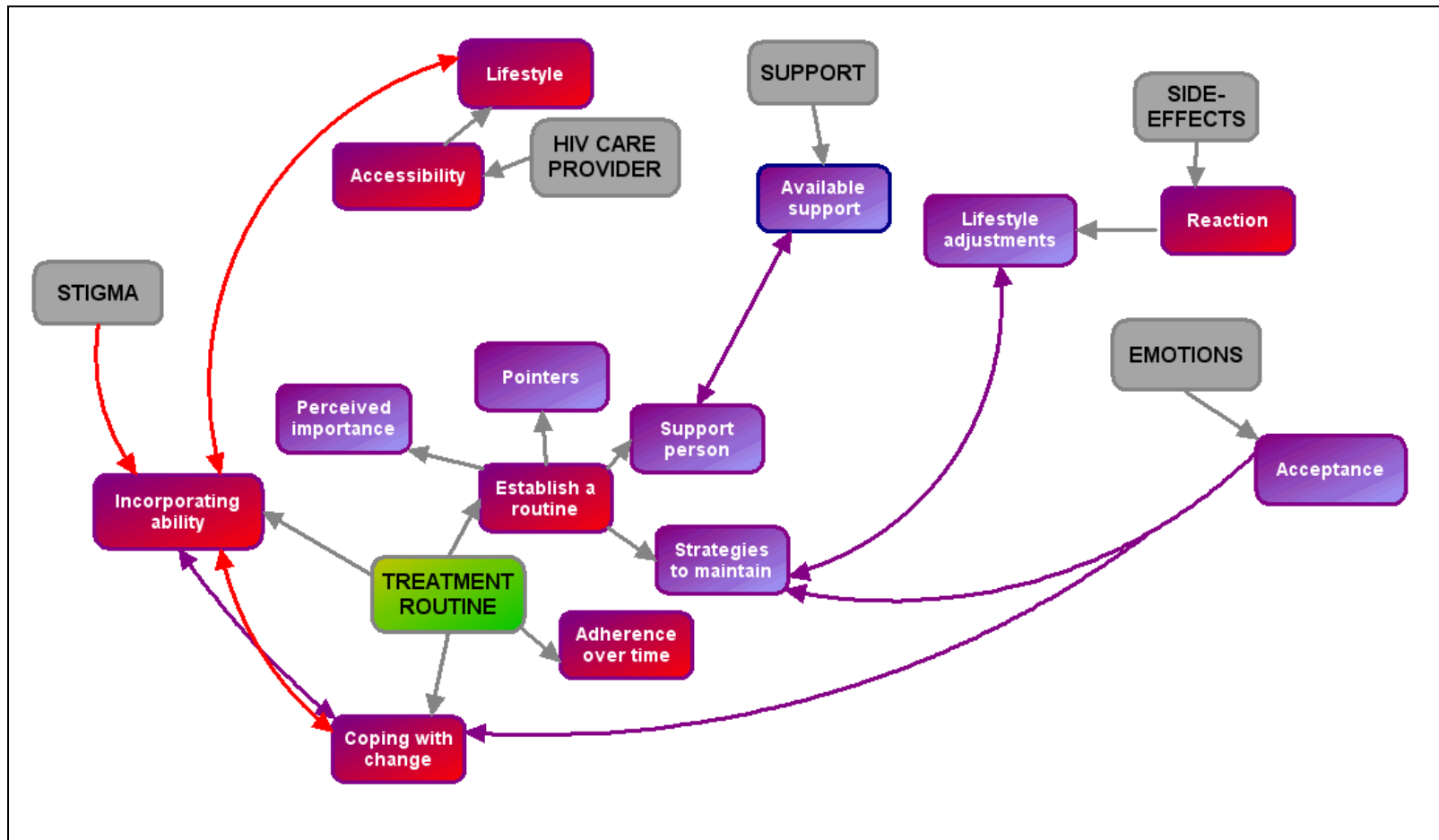


Figure 3.5.2 Aspects of treatment routine as it influenced or might influence adherence in context

3.7.6 HIV care provider

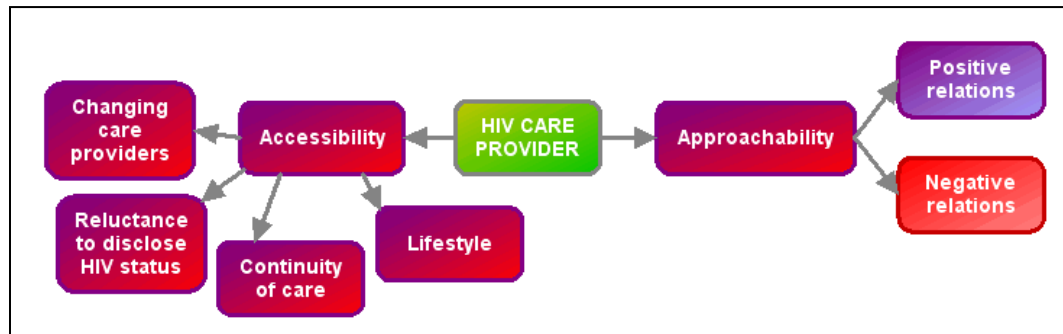


Figure 3.6.1 Aspects of HIV care providers that influenced or might influence adherence

3.7.6.1 Accessibility

3.7.6.1.1 Importance of continuity of care

Many participants indicated that they value continuity of health care. They would prefer to consult with the same doctor for all their health needs, regardless whether it is HIV related or not. If they have to consult another doctor because of their primary HIV care provider not being available, or when they are in need of specific expertise of a specialist, they felt it important that the relevant doctors communicate their findings and treatment to each other.

Coetzee *et al.* (2004: [5]) found that continuity of care and knowledge regarding each patient were considered to be important to patients. Continuity of care could be considered an enhancing factor in the level of adherence found in their study conducted in Khayelitsha, South Africa.

“... that’s why I also prefer just going to ... I don’t prefer to like jumping all over, because I’m thinking when they look at the file they’ll get the medical history from there ...”

“I prefer to go to doctor *, because he knows my status, even whatever he prescribes for me ...”

“... she knows my files and everything ... I think I prefer someone who is working with him. Someone I know and know what he would say ...”

“... if there were ... a doctor and a pharmacist, and maybe a nurse ... all working together. You must know that they are related to each other about you as a patient. I don’t want to find myself skipping doctors, going to that one, and confusing myself ...”

Even when obtaining information from a health care provider other than a doctor, for instance a pharmacist, one participant indicated that she would afterwards inform her doctor of the interaction and the resulting actions.

“... if the pharmacist was available ... I would have gone to him. But still I have to come and alert the doctor. This is happening now ...”

“... even if I go to them, but he will still know that I'm with *, and this is what ...”

In some instances, when the primary HIV care provider (doctor) is not available participants may need to revert to their family doctors or general practitioners for medical care.

“And then the doctor was not around and I went to another doctor and the said stop it immediately. Because I also don't understand these things, but if this leaflet says if there's a rash, stop, then I say stop it.”

“I did phone him and then he said he was not around Pretoria. I can go to my GP and my GP will phone him. Then I went to my GP ... he said stop the treatment ...”

As HIV is considered a specialist field, this may become problematic. General practitioners, especially those with small HIV patient populations, cannot be expected to have specialized HIV knowledge and experience. Previous studies indicated that increased experience in HIV management leads to better patient outcome and satisfaction. As the treatment for HIV becomes more and more complex with new technological advances, general practitioners are less and less expected to keep up with new trends. HIV care centers in America provide accessibility and comprehensive care for HIV positive patients. This kind of center may, however, be unacceptable to many patients due to the lack of continuity of care by one specific specialist. Although the overall service may be more extensive than a single HIV specialist can provide, it would be impossible for a specific HIV specialist to be available all the time (Stone, Mansourati, Poses & Mayer, 2001:363).

3.7.6.1.2 Reluctance to disclose HIV status to a doctor other than primary HIV care provider

For numerous reasons, participants did not want to disclose their HIV status to another doctor or another health care provider, for instance a professional nurse.

Some of the reasons stated by participants were:

- They fear a loss of confidentiality
- It was emotionally too uncomfortable to trust another person

One participant felt that she just could not reveal her status to her family doctor. She was not emotionally prepared to share this information with another person.

“... he was my doctor, but I will go to him with flu ... he’s a good doctor, but I never up to this day ... told him my status. I did never. But he was our family doctor ... I just self couldn’t ... I would just let him treat me, you know and then, forget about whatever happened to me ...”

This emotional response might be the result of previous experiences. This participant discovered that she was HIV positive through an antenatal HIV test before the birth of her second child. She was then referred to a doctor specializing in HIV. Under guidance of this doctor she commenced treatment in 1998. The HIV specialist, however, disappeared after advising the participant to temporarily discontinue treatment. This participant was left without guidance throughout another pregnancy. At the time, the gynaecologist was not aware of her HIV status. Eventually the participant confided in the baby’s pediatrician, who referred her to her current HIV specialist. In the meantime there was also an incident involving a doctor who treated her with disrespect when he learnt that she was HIV positive.

“... it’s like I found (previous HIV specialist) again. But I still didn’t tell him ... I was not honest with him ... it makes it easier ... not doing the blood tests, the HIV test ... if this is how I’m going to come out of this, then I’ll keep it that way ... I sort of like engineered, putting him where I wanted ...”

A few participants were also concerned about the level of confidentiality if they were required to consult several doctors. One also mentioned that she did not want to go to

another doctor, because then she had to reveal her HIV status and the particulars of her treatment.

“... continuity ... for confidentiality ...”

“... usually I will have to tell the doctor my status and all those things. But I would be somehow not easy ... when you are like with that doctor for the first time, he just want to know your history, form back then ...”

3.7.6.1.3 Changing from one primary HIV care provider to another

Two participants experienced loss of their first primary HIV care provider through circumstances beyond their control. Both needed to find another HIV specialist to continue their antiretroviral therapy. One participant discontinued antiretroviral therapy on recommendation of her doctor, and consequently stayed without treatment for many months. She eventually sought HIV care after her CD4 cell count started to decline. The other participant went to a general practitioner, disguising the fact that she knew her HIV status and used antiretroviral therapy before. The general practitioner tested her for HIV and then referred her to an HIV specialist as he had no experience in prescribing antiretroviral therapy.

“I went to just an ordinary GP. It was like I've started everything from scratch ... I went to him as if I know nothing. So they took blood. I knew that after the first day that the test would be positive. He'll take over, only to find he had no knowledge about ... he referred me ...”

Both participants experienced reluctance to start over at another doctor. They were both highly satisfied with the care and support they received respectively from their first primary HIV care providers.

“I couldn't go to any other doctor, start all over again.”

Some participants in this study did not commence treatment at the private healthcare facility from which this research was conducted, but were transferred to this facility for various reasons. Two of these participants relocated and had to find another primary

HIV care provider. One of them still has contact with her previous primary HIV care provider when she visits her family. The other participant mentioned that the change of primary HIV care provider was only moderately stressful as her partner was also receiving treatment at the new doctor.

"I were (on treatment at another doctor's before)."

Most participants were keen on the idea of a back-up system, where several health care providers (doctors) work together, all knowing the patients at a specific healthcare facility. One of these doctors would then be available at all times for emergency care of the patients at that facility.

"... a back-up type of system from the doctors ... I think that's a good idea ... people have different ideas about everything ..."

"Even if it's not the doctor himself, but somebody that is related to the whole situation ... it can be like an emergency ... when a person has your number in an emergency they want to talk to you ..."

"... unless he is going away for some weeks ... maybe if they send me to the other doctor ... it can become worse while I'm waiting ... someone that can help me ..."

3.7.6.1.4 Lifestyle and accessibility of primary HIV care provider

A busy lifestyle, working hours and restricted consultation periods, seemed to be factors that deterred participants from adhering adequately to follow-up consultations and laboratory tests, as part of their treatment.

"... it's hectic in the morning ..."

"... my doctor he can only see patients after a certain time ..."

"I'm a very busy person."

"... there is not time, too busy ..."

Some participants indicated that they would prefer their doctor to be available during weekends, or at least one weekend a month, so that they would not need to take time



off from work.

“... usually weekends, at least, I’m around ...”

“... one weekend a month ...”

Leaving work to go for a doctor’s appointment, laboratory test, or to collect medication, was pointed out by several participants, as being problematic.

“... my work also, it doesn’t allow me to, every time, go see doctors ... is it available at four. Or after, past four ... I don’t want to take time of at work ...”

“I will have a problem leaving my work somewhere around 11 o’clock, coming ... in town, coming this side. And then have to go back.”

“... the problem is that I’m working, and the transport ... every time I have to ask them and then they drop me here ...”

Only one participant indicated that she did not experience any problems with her employer when requesting to leave work for a doctor’s appointment.

“... if I told them I’m going to the hospital, they allow me ... because ... I was very, very ill ...”

One participant reported that her going often for appointments at the doctor, awakened curiosity in some of her co-workers, who wanted to know why she has to visit the doctor so often. She had to lie about it to keep her HIV status secret.

“... they do ask, why are you going to the doctor every now and again? ... I say no I have to do the check-up because of the meningitis I had ...”

Other participants said that although they find the doctor’s consultation hours inconvenient, they abide to it. They understand the problem of always being available and make a plan to attend follow-up consultations.

“I don’t have a problem with that, because I don’t have time either.”

“I don’t have problems with logistics of making an appointment ... my doctor he can only see patients after a certain time ... for me which is inconvenient, because I stay near, the hospital, so I would kind of prefer kind of to perhaps go in the morning. But it’s not possible, but it doesn’t

worry me, because I can go later on in the afternoon.”

“... with me it's not a hassle ... it's something that all in my diary, I know that this date I must see my doctor, talk to my doctor. And for me, even if it cost me to come to the doctor three or four times in a week, I will do that. Exactly that, because if I don't understand something, I will make sure that I must see the doctor and let him explain to me why this ...”

3.7.6.1.5 Accessibility of providers

Perceived accessibility

In case of an emergency, many participants indicated that they wanted or would like to contact their primary HIV care provider. It was often easy to secure an appointment.

“... he was very accessible ... to get an appointment with him ... it was easy. I would phone him and say doctor *, this is my situation, where are you. Even if it was Sunday or holiday, you will make an appointment, and I'll be there ...”

“I would be sick now and fear now, and drive now in the middle of the night and go to him. There would be immediate tests and everything ...”

“... the following day I came here and I told doctor * I'm a bit worried, I was in the mountains, and I think I'm not feeling well ... we did a test, I think it said broncho-pneumonia ... that scared me ...”

The circumstances in a busy medical facility can change suddenly. Assistance regarding specific HIV related queries may not be available when needed. The medical facility where the study was conducted, was incorporated in a large hospital set-up. Patients, and therefore also participants who could not be helped at the medical facility, were either referred to the emergency unit of the hospital or to their general practitioners.

Some of the participants reported that they had the doctor's cellular phone number and will contact him when they needed help.

“... we have the doctor's cell, we were able to call him. He was able to give us advice and directions of what to do ... I think he is accessible ... you just adjust yourself ...”

“I can always phone doc and say, I have one day's extra dosage, but I now need to stay for more, can you fax me something where I can get my medication ...”

“I have his number.”

One participant expressed disappointment with her primary HIV care provider for not being available when she needed help. The participant rationalized that the doctor could not be available at all times, but when patients had questions they need answers. The unavailability of the primary HIV care provider, with no identified source where the participant could turn to for help, brought forward underlying fears of death and disease. These emotions often motivated participants in this study to act promptly when they experience unfamiliar symptoms.

“But if I can’t find him, they say it is full. I understand there’s lots of other people, there’s thousands of other patients, but, think about it, what if I was dying at that point in time.”

“... if the doctor was around, because I kept on phoning him ... he said I should go to Med24 if the rashes itch and then worrying me ... he said he will be around on Monday.”

“I’m troubling now ... to get the appointment ... I don’t want him ... to be burdened by me, but surely I need some surety ... it’s full ... suppose I was dying by that time, then what? Why do I have a doctor then? But you still don’t see the doctor ... that means I’m just a statistic ... I didn’t like it.”

“I can’t secure an appointment with him because it’s so busy, up to now ...”

“... if you are sick you want help, there and then ...”

Accessibility of assistant providers

Providers of laboratory services and pharmacies became more and more accessible through the years. Currently, most hospitals have a pharmacy and laboratory with extended or 24 hour services.

“... the laboratory or the pharmacy ... I think it should be accessible for people ... in my opinion I think 24 hours. The doors should be open ...”

“I didn’t receive my medication for quite some time and then I phone the ... chemist ...”

None of the participants described these services as inaccessible. In fact, most participants were satisfied with the service provided.

“... the laboratory ... very fine ...”

3.7.6.2 Approach of health care providers towards people living with HIV and AIDS

3.7.6.2.1 Positive relationship with health care providers

Many participants reported positive experiences with the health care providers they came into contact with.

From a study conducted in Botswana, most participants indicated that they had a positive relationship with their health care provider. They reported feelings of respect and support. These participants also indicated that these relationships had a significant impact on their lives. Patients often perceive doctors and nurses as primary sources of support. Most patients felt more comfortable talking to their primary HIV care provider about antiretroviral therapy, than to anybody else (Weiser *et al.* 2003:283-284; Cinti, 2000:[6]).

Adherence can be positively influenced by the presence of supportive nurses as it has an influence on patients' willingness to attend follow-up consultations and collect their medication. In a study conducted by Rowe *et al.* (2005:266) this specific factor was mentioned by almost all the participants. Additionally, Squires (2003:[6]) found patients needed psychosocial support from their healthcare providers. The support and information that forms part of such a relationship have a vital role to play in enhancing adherence (Weiser *et al.* 2003:284).

Rowe *et al.* (2005:268) suggested basic interventions that health care providers can consider to improve patients' adherence to antiretroviral therapy. They suggested that the environment of the healthcare facility should be welcoming. Care should be taken to maintain confidentiality while personnel display an encouraging, friendly and supportive approach. Services should also be stream lined to minimize waiting time for patients.

Participants in this study referred to various positive impressions related to their

primary HIV care provider and other supporting providers. These impressions are summarized in Table 3.1

Table 3.1 Positive impressions of participants in relation to their healthcare providers

<p>Being treated as a normal person</p>	<p>“... and the sisters who are assisting him I never felt like, ugh, it’s another month ...”</p> <p>“... there was no special accusing like if you go to a doctor ... you know these people, talking about me, or I was confident every time I went to that surgery ...”</p> <p>“... the staff are professional ... obviously they work with our files, so they might know, whatever our status is, or what have you, but I see people smiling, people talking, treating you as a person, as a human being. And I think, that just give you value ...”</p> <p>“... one of the sisters, I think she’s left now, we developed a rapport to an extend tat I would go to the doctor’s place just to pick up my medication, but I budget like 15 extra minutes because we would just be chatting about anything.”</p>
<p>Being put at ease by the doctor and personnel</p>	<p>“... he has a warm personality and sometimes you know, when you got to the doctor, you see, you are kind of tense, and he just talks about small little things, the economy, politics, small little things, just to put you at ease ...”</p> <p>“... you are feeling like part of his, his practice, his family, because he is telling you all these stuff ... you are not just a statistic ...”</p>
<p>Receiving information regarding treatment efficacy and treatment plan</p>	<p>“... he looks at your results, he explains, he says whatever in medical terms, I always say to him, OK, but what does it mean in laymen’s language. Talk to me as a laymen, and then he explain ...”</p>
<p>Participants trust health care providers</p>	<p>“... the only person that can say no it’s fine, it’s OK, is your doctor ...”</p> <p>“I’m relaying on his expertise.”</p> <p>“... white nurses provide more security ...”</p> <p>“I have to feel at ease. At least the doctor is the only person that knows what is happening within my health, and I should trust him with my life ...”</p> <p>“... it’s important to trust your doctor ... doctors are also human, they make mistakes ...”</p> <p>“... the personality thing ... I think if you then don’t develop that rapport with your doctor, there’s kind of a trust factor. If you realise the doctor is a professional, he knows his stuff, and you put your life in his hands. So that trust, if it’s not there, then the mindset also, that you’re going to heal, or you’re going to be fine, does not</p>



	<p>settle. So I think it's important ..."</p> <p>"... (do you think you don't want to question his decisions because there is not that relationship between a doctor and a patient in the beginning?) ja, something like and then you just think, OK, the doctor knows everything ..."</p>
Health care providers are approachable	<p>"... the two doctors I dealt with, they are approachable ..."</p> <p>"... they are always willing and prepared to help you ..."</p>
Health care providers treat participants with respect	<p>"... they just take the blood ... give me the results. No questions ..."</p> <p>"Firstly I was scared maybe they will ask me questions or what. Especially if I'm treated maybe by African black ladies. I thought maybe they will ask me some other questions, what happened or what-what. But they are OK."</p> <p>"... respect the confidentiality ..."</p>
Sensitivity towards the patient as a person and not just a case	<p>"... doctors would treat us as sensitive as they can, with love, with care, with compassion ..."</p> <p>"I think he understands what I'm want of him ..."</p>
Health care provider offer emotional support	<p>"I'm looking for a doctor in this hospital whose going to help me through this"</p> <p>... the doctor ... maybe if he can contact me once a month, or just to find out how am I doing ... am I OK, am I taking my medication ..."</p> <p>"... and he also gives me courage sometimes because my CD4 levels are coming OK ..."</p> <p>"... all those patients, it doesn't matter how long they are staying in there. They are not going to up and go because they know when it's their turn to go in, when they get out of there they will be feeling good about themselves. Forgetting the fact that they are dying ..."</p> <p>"... if I had any fears I would come out of here thinking that I'm going to live 20 years ... he made me feel so good, about my situation, that I'm probably I'm doing the mistake of trying to compare other doctors to him ..."</p> <p>"He was very good for me ... so close, that whenever I was depressed or anything ... I was actually looking forward to my life with my kids ... a good future ..."</p> <p>"... the relationship was good ... then he vanished ... he was nowhere to be found up to this day I was shattered, shattered ... it shattered me, he was the closest person to me ... I couldn't go to any other doctor, start all over again ..."</p> <p>"... the treatment he gave me was, was not right at all. Because at that stage I felt I needed support. And as my doctor, I thought he was even going to give me more information about the disease ..."</p> <p>"... even the information and the ... sort of counselling I got from the first doctor ..."</p>



	<p>“I fell in love with this man ... he was a friendly person, he would counsel me ... he was my lifeline ... I accepted everything ... that is what I want ... I'd like my relationship with any doctor to be the same ...”</p> <p>“... she tried to motivate me. I know of many people ... please don't be disgruntled or anything. I know many people who can resist, who can survive, don't think tomorrow you will be dead or you'll be sick in bed or you'll be something ... he managed to get his other health back though he still have the virus ...”</p> <p>“... he had all the time ... it took away the uncertainty ...”</p> <p>“I was not free, and that doctors too, they made you scared. It seems as if you are going to die tomorrow, today. The way they talk to you, actually that was cruel.”</p> <p>“He never said much. He said no you're not dying ...”</p> <p>“... (the doctor telling you on the phone that you are HIV positive) very bad. I never want to see him again. I have been consulting with him ... for years, and he knows I've got a clean record ... I felt we had some sort of a relationship that could have made it ... a bit easier ... or he could be ... a bit human ...”</p> <p>“... even the information and the ... sort of counselling I got from the first doctor, he told enough maybe ...”</p>
<p>Health care provider are honest towards participant about HIV and its treatment</p>	<p>“Should open up, not hide anything ...”</p> <p>“... be honest with me because I need to know ...”</p> <p>“... you're going to be straight with me. You just tell me what has happened ...”</p>
<p>Matters regarding the participant are treated with confidentiality</p>	<p>“... the idea of the medication being delivered to the doctor's rooms, is ... for me, it's absolutely important ... because I could imagine, if I had to go with a prescription and buy from the pharmacy, those steps it would take to get me to the pharmacy, they would be heavy. But now, everything is wrapped, it's in a box ...”</p> <p>“... they can destroy you ... I think it should be confidential ...”</p>

3.7.6.2.2 Negative experiences with health care providers

Some participants had negative experiences with health care providers (See Table 3.2.)



Table 3.2 Negative experiences of participants in relation to their health care providers

<p>Loss of trust towards health care provider</p>	<p>"I did another x-ray ... which I now I insisted to look at it myself"</p> <p>"It's like with our black culture, it's more about openness, if you are open to the people, and then people will also be open to you. But if the way you are treating them is like you put something like a * and then they will also be afraid of you"</p>
<p>Loss of respect of health care provider</p>	<p>"Me seeing him was at my own request, because he didn't want to see me. He just said I can give you numbers of people that you can consult. And I said no-no-no, but I need to understand what are the implications of all this. Can I please see him? And then he said ... you can see me only after two days ... and also being a person that I've seen for years ... I'll never recommend him to anyone"</p> <p>"The doctor came and he say ... I don't know what's wrong with you ... and he was shouting ... it was in the ward. And it was like ... I tested a lot ... we need to do an HIV test. And my husband said, he just like felt like, please the world swallow me. Because there is already that assumption that ... if we can't find anything wrong, then perhaps the HIV will confirm"</p> <p>"I got the feeling that he's like 'you've got AIDS, I don't want you here'"</p> <p>"Then I decided no, I'm not going to go to this man ... I need to deal with this but I'm not going to go to this man ... I don't think I liked him as a doctor for me"</p> <p>"If you go to the hospital and you find that that one is shouting at the people, rude and what, then they will withdraw, and then they are afraid"</p> <p>"As my doctor, I thought he was even going to give me more information about the disease"</p> <p>"I can't go to the other doctor, I need to talk to you, find out exactly, you know, because at that stage I was got so frightened, then I thought maybe, because those days it was like you can die tomorrow"</p>
<p>Feeling of loss of confidentiality</p>	<p>"I felt like that, now most people are knowing my status, but I also think all these people are from, it's like a doctor, they will end up knowing ... it's fine with me, as long as they understand. The problem is when someone doesn't understand"</p> <p>"The government hospitals, you find that the nurses they don't even treat them well. It's like they are afraid, or the reception that is only for HIV ... I (will) never (go there), because I'm afraid to go in there"</p> <p>"When the teenage ladies used to go to the clinics to get their injections ... people didn't want to go there, that way some got pregnant because of the way the nurses were treating them"</p>



	<p>“When I came here the doctor examined me and thereafter he told me I’m due to go on treatment”</p> <p>“When they changed it, I just received a phone call that your medication has changed ... (did you felt left out) ... Ja, in a way ... ‘doctor why are we changing this medication?’”</p> <p>“I would have called the doctor if we had not discussed it ... simply say my medication seems to have changed, is there any reason for it, I would ask. I would ask questions.”</p> <p>“He seemed unaware of why it has been changed. Because he said, he didn’t have a discussion with the doctor, he just found out, but he reckoned from retrospective, he reckoned that the three has now be combined into one ... he seemed to have blind faith”</p> <p>“So I asked him, why am I not drinking these but that? He said, no-no-no, I’m putting you on this one ... if it proved to be problematic, because I will be monitoring you, then I would change it. but when I see your results, there is nothing and also you’re not experiencing any problems maybe you should stay on it”</p>
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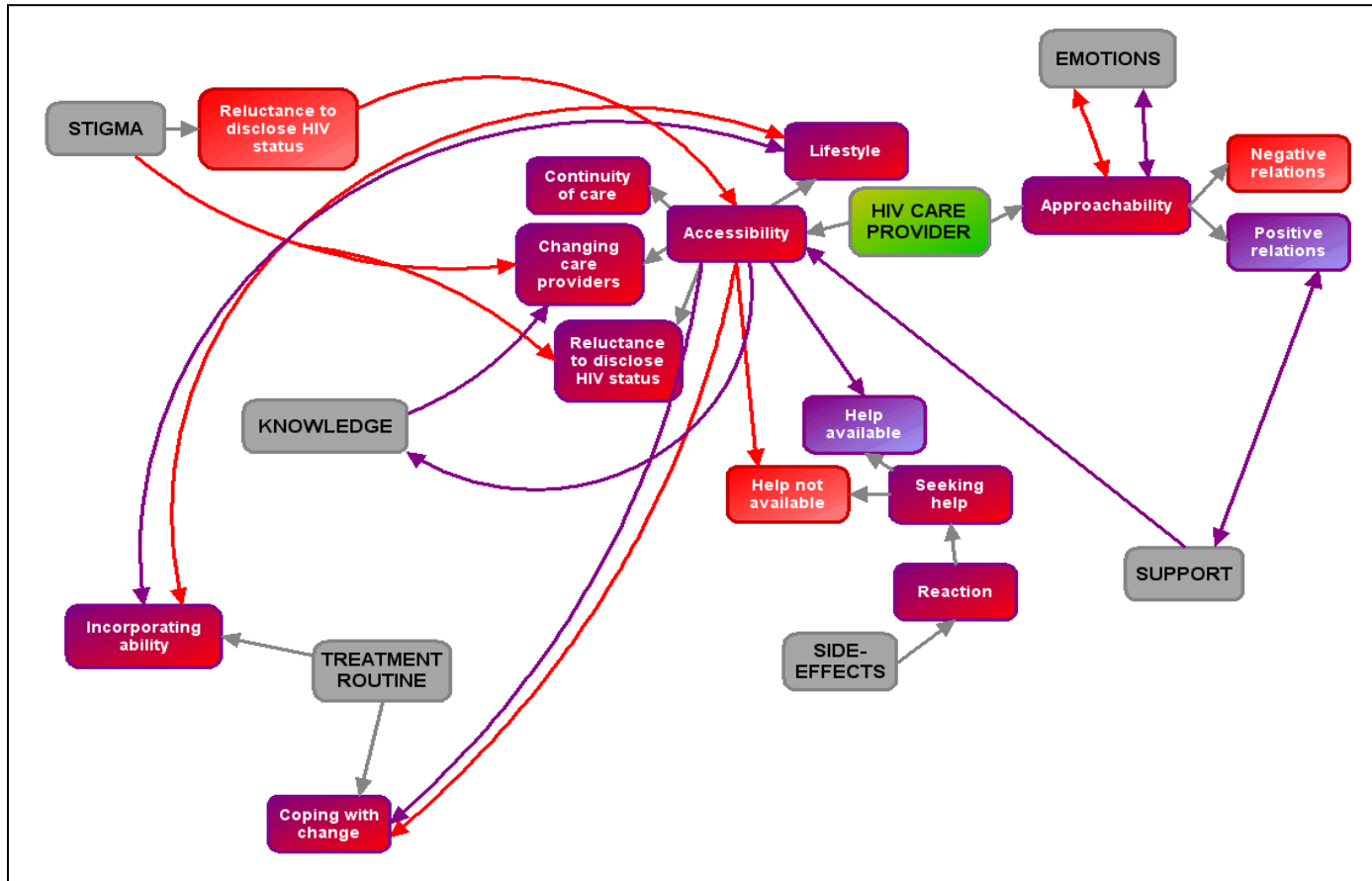


Figure 3.6.2 Aspects of HIV care providers that influenced or might influence adherence in context

3.7.7 Knowledge regarding HIV and antiretroviral therapy regime

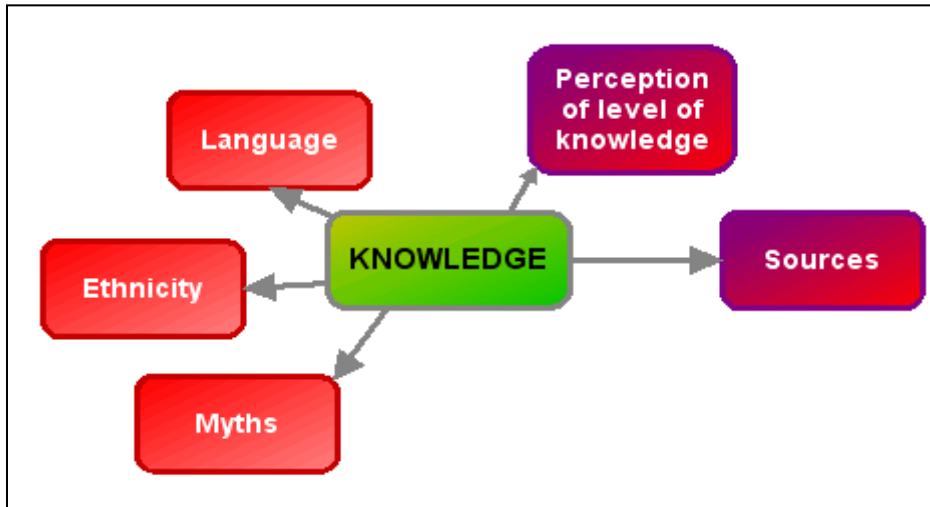


Figure 3.7.1 Aspects of knowledge that impacted or might impact on adherence

Knowledge regarding any subject, be it HIV and antiretroviral therapy, or cardiovascular disease and diet, is generally considered to be beneficial in preventative and curtailing measures of a disease.

Knowledge regarding HIV was positively associated with self-reported adherence in a study by Weiss, French, Finkelstein, Waters, Mukherjee and Agins (2003:677). Supporting evidence was found in several other studies testing the relation between adherence and knowledge regarding a variety of medical conditions

There are a number of reasons why this relationship may exist. Knowledge of medication instructions is certainly a precondition for adherence. Knowledge may also promote the development of adherence related skills (such as scheduling) and may increase motivation. It may also be that knowledge is a proxy for motivation: a person who makes the effort to learn about an illness will also make the effort to control it (Weiss *et al.* 2003:678).

Tuldrà, Fumaz, Ferrer, Bayés, Arnó, Balagué, Bonjoch, Jou, Negro, Paredes, Ruiz, Romeu, Sirera, Tural, Burger & Clotet (2002:[6]) illustrated in their study that a combination of psychological and educative intervention impact positively on adherence. The experimental group was subjected to specific intervention based on Bandura's self-efficacy theory and on excellence in clinical practice. Patients in the control group underwent standard assessment and follow-up with a psychologist. In this study the experimental group displayed an adherence level of 94% compared to the 69% of the control group. Knowledge should be imparted early or even before treatment commences, to minimize the risk of resistance.

Although a lower educational level is associated with greater incidence of intentional inadequate adherence, this phenomenon may be explained by the possibility that people with a lower level of education may have greater difficulty in understanding foreign concepts. They may also be less able to voice their concerns regarding their treatment difficulties (Heath *et al.* 2002:[7]).

"... the amount of tablets you take is not as important as the effect it causes ..."

"... if I went and go and check, it says negative, but it doesn't mean the virus is not there ..."

"... to me it's not the amount of tablets, it's got more to do with what stage you are at in terms of the disease. What would work best for you at that time ..."

"... when your viral load is low it doesn't mean that you don't have HIV ..."

"... he's giving you a different medication because your systems are not the same ..."

De Bruin *et al.* (2005:390-391) noted in their study that a lack of knowledge regarding adherence, ignorance on what comprises correct medication taking and being unaware of behaviour supporting inadequate adherence, to be reasons for inadequate adherence. From this study it seems that most patients lack adequate knowledge to develop skills for optimal self management of their treatment regime. Improving patients' understanding of adherence leads to better self-efficacy, increased self-monitoring of adherence and greater motivation to change behaviour that interfere



with adherence.

People who are not knowledgeable on HIV and its treatment are likely to succumb to fear and speculation. They are also prone to believe myths about HIV. People who have the knowledge will not only know what to expect, but will have freedom in taking part in treatment decisions and are more likely to access medical care when needed.

“... if they want to know about this disease, people will be free ...”

“... if they can know what to do, why they must do this, what are the implications if they stop taking the ... because sometimes they are just taking the pills ... they can maybe try and change their lifestyle also ...”

“... it's nice to know so that you can be prepared ...”

“... it's important to stress adherence and to explain the implication of not adhering to the treatment ...”

“... from now onwards I think it's like I have to be concerned whatever is happening. I have to know exactly what is going on ...”

“... will I still be able to use this medication after stopping it? It's almost a month now ... it worried me ...”

“A preparation session before commencing treatment is important.”

“... it's also an issue that I had to sit down with my partner and explain to him that I'm now going to be taking this and this is what they look like, and this one goes into the fridge. And this is what I take. That he, if for me reason I'm not able to do this for myself, he knows that ... when at this time, I must take this. It didn't get that far ...”

“... (do you think the fact that you are more educated than many others, helps you to talk openly to the doctor?) ... yes ... the previous doctor I was at teaches me a lot about this disease. I feel I know a lot ...”

“I'm dealing with a disease that is very, very chronic, and I didn't know what to expect ...”

HIV becomes part of a patient's life, and she needs to know what is going on in order to be able to plan and adjust.

3.7.7.1 The influence of language and ethnicity on HIV education and subsequent adherence

A pilot study done in Ft. Lauderdale, Florida, found language barriers a potential factor that influences adherence to antiretroviral therapy. Participants who were able to reach an undetectable viral load always had an interpreter or translator present during their clinic visits. However, the participants who were not able to achieve virus suppression had only minimal intervention by an interpreter (Jones, 2005).

According to the New York State Department of Health AIDS Institutes (2001) Best Practices Guidelines strategies addressing language barriers should specifically be implemented to facilitate adherence. Some of their suggestions are:

- Signs should be in the languages spoken by the patients visiting the facility. This may help patients to feel at ease and identify the site as being comfortable.
- In a multilingual population the staff of a health care facility should be representative of the languages spoken. Even patients who can speak the common language, usually English, may have difficulty understanding some concepts. It is not always easy to translate these concepts via an interpreter.
- Written and printed material for example pamphlets, should be available in all languages spoken by the population served at the health care facility

Dr Orrel and colleagues (Smart, 2005) from the Somerset Hospital in Cape Town reported that many of the participants in their study lived in extreme poverty. However, the only factors positively associated with poorer adherence were youth, three times daily taking medication and language proficiency. Inadequate adherence had been more severe amongst participants whose native language differed from the language spoken by the health care facility personnel.

Some participants in this study indicated that language may pose a problem and that a

technique of verification should be used to overcome this problem. Patients should be put at ease and encouraged to ask questions. Patients should be informed that they should stop the health care provider if they do not understand.

“... you and me can both speak English and still not understand each other. We may understand different things from the same language. But I ask if I don't understand, or I'll correct you if I think you misunderstood me, just like you do ...”

“... you can tell them if they don't understand they must ask whatever ...”

“... new information ... and then you start to treat it as new information, then they would say, I mean, that has been my point all along. But you never said, or it never came out ...”

In circumstances where a healthcare provider has real difficulty to converse with a patient, it may be necessary to employ the services of an interpreter.

When making use of an interpreter or translator, the health care professional should apply special care on the selection of this person. Although family members might be more convenient and available, patients might be reluctant to discuss personal matters in front of or via a family member. Care should also be taken that the interpreter understands what he/she is translating to prevent confusion and misinterpretation. It is therefore advisable to make use of a professional interpreter (New York State Department of Health AIDS Institutes, 2001).

“... you'll find that they've got a problem, they don't understand English, but it's not that difficult, maybe you can find the nurse who maybe speak their language ...”

“... for me it's fine in English, as long as I understand. And where I don't understand, I'll ask. Maybe if I still understand if they can then get somebody who speak my language ...”

One participant referred to an incident where she observed another patient talking about her visit to a doctor who could speak her native language. From what was being said the participant assumed that the patient was impressed and felt that she was important enough.

“... you could see her excitement when she learned that the doctor could speak Zulu, OK, so she is like human after all, she can speak my language, she's human ...”

Two participants indicated that factors other than language can pose a problem with effective communication, such as the attitude of the health care professional, power and class structures.

“... it might be a language problem, but I think ... the power structures, class structure, things that play a role ...”

“... but it's got to do with the attitude of the nurse ...”

“... it's as if you have already been put in a box where you are representing a certain class and structure ... if she's a white person she must be a superior being ...”

“I don't know about the younger ones, but us, the older ones, we look at the influence of apartheid. And the effect of subjecting certain groups and whatever the ... because there you are an embodiment of white superiority. I doubt if they are actually seeing you as a, because, I heard people say, I would prefer to see a white lawyer. And I'm what is the difference? ... inferiority complex ...”

“... what you say is gospel, no questions asked, that kind of thing ...”

“... we learned to keep quiet, not to complain or stand up and say what we think ...”

It is therefore extremely important that health care providers maintain an open and non-judgmental approach when working with patients, as described by one participant

...

“... a talked down approach ...”

Some participants indicated that the race, and not the gender of their health care provider, played a role in the level of initial trust they instilled.

“... especially the white doctor, I think they trust more than the black doctors ...”

“... with the males, they always have problems to go to the doctor. But with us females, especially if it's a white doctor, regardless if it's a male or female, they do trust ...”

“I wouldn't have issues about colour, I wouldn't have issues about gender of the person. If I do have that conviction and enough information on me to know this is an expert, this is a professional in their field ...”

In the end, the care and attitude with which information was imparted, played a greater

role

“... the first one, you know everything ...”

“... more transparent ...”

Most participants indicated that their doctor informed them on treatment related issues and how to drink the medication.

“... he told you, you must take it twice a day ...”

“... because Mister (*doctor*) said I must make it the same time ...”

“... (*did anyone before explained to you that the medication must all be taken?*) yes doctor ...”

“... the doctor explained to you why you should start on treatment ...”

“I knew I would stop, the doctor has told me that. I take it for the baby now, I don't need it.”

“I'm doing exactly what doctor * has told me, and I'm taking the medication ...”

“I used to know exactly what was happening in my health ...”

“... he'd look at the results and then: OK this is what he want to do ... then I'd ask him what is my CD4 count ...”

“... as a results I was very much educated about my status ... I'd go for tests ... he would break down every thing ...”

“... the doctor told me I must come again after three months. He must see how the ... he talked about the CD4 level, but I don't understand what that ... I must come for the blood tests, what's going on ... the first time he said it was fine ...”

“... most of the time he used to tell me, like when I'm going for a test, and tell me my CD4 level today ...some of the things I do understand ... some of it I don't understand this ... then he try to explain again ...”

“... he told me almost everything. He was like, he take time and he tell me everything that was ... my results, what is happening. What is going on. He also told me this is not going to cure me ... but is like, boost my CD4 count and all those things ... she also tells me maybe I might be resistant to the drugs, so I was scared ...”

“... the doctor was telling me that some ointment ... it doesn't go together with the treatment that I take ...”

“... he don't talk too much. He just tell you no, do this, do that ...”

One participant stressed that it is important that healthcare matters be explained in a way that is easily understandable. Health care providers should not be confused by a patient's level of education and assume that highly educated people will automatically understand medical terminology.

"... if I sit with the doctor and they explain to me ... I'm like, please put it in laymen's terms for me. Don't tell me numbers or what have you, because I don't know what numbers mean. So they say OK, what it means is when they are pushing scientific terms, I'm getting confused ..."

Miscommunication or misunderstandings between a patient and a doctor can lead to feelings of anger and mistrust. Health care providers should take great care in ensuring that patients understand correctly what are expected of them.

"At that point in time I was also angry about drinking nevirapine for 3 weeks without other medication. And also the blood thin, because blood was coming here and also here ... it was wrong for me to take nevirapine alone ..."

"... he didn't explain that you don't take everything at the same time. So he told me after I've spoken to him, he said you take one in the morning and one in the evening, and the others you can take all three at the same time ..."

"I think we misunderstood one another because he gave me a prescription ... that only had Viramune ... he was like no, I never said ... I got you the nevirapine and the Purbac, I wanted you to combine them. So I said you didn't explain, you gave me a prescription that said Viramune, so I didn't understand, whether OK, this one I was supposed to take it there ..."

Several participants indicated that various factors may prevent patients from asking questions. As it may not be easy to determine all these possible factors, health care providers should probe patients to determine their level of knowledge and understanding of the issues in hand. An open line for conversation regarding HIV and antiretroviral therapy may facilitate knowledge seeking behaviour when patients develop a need for it.

"... you might not know that you have questions until you get home and start thinking about these things. Then they need answers and may fill the blanks with wrong information if they don't have easy access to a reliable source ..."

"... ja, they've understood yes, but then is there really analytic and critical thinking around what's been presented to you ..."

“... some people don't ask questions because they are afraid of the answers. They should be drawn out by the doctor or someone else ...”

“... ja, it's like a lot and sometimes you don't feel like asking because you've never done this before ...”

“... they just say stick to your medication the right times. And then they don't go beyond that ...”

Participants also indicated a need for more specialized information. Usually the information that is introduced when patients are diagnosed with HIV and/or when they commence with treatment may be enough for a while. However, other issues and questions emerge in time and patients need access to accurate and understandable information.

“... specialized information ...”

“... more information as to how you can get resistant towards the drugs. What are the causes. How do you recognize the effects of when you are resistant rather than sitting waiting for when you go for the regular testing ...”

“... it's when you don't have information that it's very disappointing ...”

3.7.7.2 Myths and misconceptions

Participants tend to rationalize their treatment. For instance, one participant commenced treatment with three different drugs. When a combination tablet of two of the three drugs became available on the market, the doctor prescribed it. This participant interpreted the reduction in amount of tablets as a sign that her health is improving.

“I was very ill, so I had to take this three, and then I saw, OK, now it's one. To me it said I'm fine taking only one tablet ... maybe my CD4 count was too low or this viral load was too high so that's why I had to take three ...”

Any change in treatment, even if a patient switch to a generic equivalent should be discussed with the patient. Some participants thought their medication changed because the name of the drug changed, while essentially it is the same medication.

One participant attributed myths and misconceptions to a lack of knowledge and the influence of culture on people's thinking.

"I think because of, they lack information, or ... you know our culture, I think the cultures too, they make this thing very much difficult because mostly the black people, they will tell you lies about HIV and AIDS. They say they can cure it, they can do whatever, but there is no such. I don't believe that. But there's lot of stories, from them ..."

"... people believe, especially if you are not exposed, if you don't do this research on your own, people believe whatever ..."

"I think we are not well informed ... knew a little bit ... I didn't know as much as I know now ... now that I've had time to go and find out, but I do, I do listen ..."

"I don't know if they really, also like, if its really as effectively explained and very simplified for lay men ..."

"I think if they can have this information, you won't get suicides and all this rapes. You know if you rape an innocent baby, you rape a young child, because they got the information that if they are HIV and sleeps with a ... like a virgin, and you gonna be cured. There was no lies. Even if I read books after that, it was exactly what he said ..."

... "and you don't believe it because you know now from other sources that this is how the virus works ..."

"... but now, most people are getting educated, I think it's only that old ones and mostly from rural areas, ja, I can say, ja, they are still believing that ... the less they know about it, the more the culture rules, the stronger the culture is in what they do and believe ..."

"... so it's a lie ... if you don't know anything about HIV, then you might believe what he says ..."

"... education plays a major role ..."

"... educating a person about his/her disease will help to reduce the social gap between the doctor and the patient ..."

"... maybe I can broaden their horizons by telling them ... life is a learning experience and they are also learning from you ..."

Another participant indicated that fear, especially towards HIV and the stigma surrounding it may deter people from determining their status.

"... people are still doubtful, but I don't think it's a thing of doubtful, maybe it's that they don't want to go for the test. They are afraid, but they will take it as there is no such ... maybe if they can go for the test, then they can see that thing is real ..."



Some of the misconceptions encountered by participants were:

<p>HIV can be cured by traditional medicine</p>	<p>“... they’ve been given a potion to drink, and then after three months it will go to the stage of undetected. That’s a herb from a sangoma ... I made sure that I don’t drink anything that is herbs that I’m not sure about ...”</p> <p>“... he made me a little bit curious, although I know that I don’t want to use anything, anything that has not been tested, you know. I don’t want to put my life, you know, if I have to die, but I don’t want to ... you know, give the virus that ... it develops quicker and faster by doing things that I’m not sure of ...”</p> <p>“... he’s believe, he thinks that it can be cured. That HIV can be cured out of the system ...”</p> <p>“... people believe it, because someone told them that is a way to get cured from HIV. It’s not a cultural thing ...”</p>
<p>HIV can be cured by virgin rape</p>	<p>“... some sangoma or somebody started to spread the idea that you can be cured from HIV by having sex with a virgin. I don’t believe it ... I’m more educated and read on these things for myself. I think it more affects the people in the rural areas. They are still very much influenced by their culture”</p> <p>“... sleeping with a virgin or sleeping with an old lady ... the issue of it being a curse ... it really has to do with escapism and not really wanting to face acts, not because hey don’t know what it is ...”</p> <p>“... the rapes of minors, but it’s not true, no, I don’t believe in that ...”</p>
<p>Causes of HIV</p>	<p>“... maybe I’m a widow ... so it you can’t go for that and you met the other one and fall in love with him, then you’ll get HIV ...”</p> <p>“... they are always accusing the whites ...”</p> <p>“... a person then starts to loosing weight and ... because people also call it slim disease ... it is as if there is a snake inside you. And it’s eating you and that snake is really, it’s actually as if you were bewitched. Then perhaps if a person thinks if I have sex with a virgin, ant then that snake is going to go out of me and going into her, and then, at that level, it might make sense ...”</p>

3.7.7.3 Sources of information

Of the many sources that patients draw from for information, specialist HIV health providers were considered to be the most helpful sources of information. The hospital consultant (attending physician) was viewed as helpful or very helpful by 83 patients



(75%). Seventy-seven (70%) found the hospital pharmacist helpful or very helpful and the hospital nurse was seen as helpful or very helpful by 56 (51%). Other HIV-positive individuals (45%), the Internet (43%), publications other than medical books (43%) and voluntary organizations (42%) were also viewed as helpful or very helpful sources. Patients tended not to use local chemists (pharmacists), their general practitioners, patient groups or social services for information about HAART (Gellaitry *et al.* 2005:372).

Patients' adherence directly correlated with the health care provider's beliefs regarding the efficacy and importance of antiretroviral therapy. Health care providers therefore play a vital role in educating and guiding therapeutic decision making (Squires, 2003:[6]).

Participants in this study obtained their knowledge regarding HIV and antiretroviral therapy from two broadly organized groups, named for the purpose of this study:

Formal: Professional or scientific information

Informal: Social information

Formal	
Medication information pamphlet	<p>"... that pamphlet, cause it is with Combivir they've got a paper that they put every month, please take your medication at the same time everyday, so that it could work. So that paper, the pamphlet that I've got from them said the same thing ..."</p> <p>"... scary pamphlet, I could have learned from doctors ..."</p> <p>"... when I read the pamphlet I said, once you stopped it, don't start with it again. Try something else. And now the doctor said, no , you go back. And I said doctor rash and itching, my eyes ... there's no other treatment that's better than this one. The rash will eventually vanish and you will get used to it. I think it's working. So I started drinking it again ..."</p> <p>"After reading the pamphlet, I read something like fatal rash, in my mind fatal rash means you're dying. A fatal rash it can kill you, you know? But now he was assuring me that it's a good medication, and I must continue the treatment, the rash will be finished gradually ..."</p>



	<p>"... (do you believe in gathering information for yourself and make your own choices?) Yes ... but I don't read books, not exactly, even the pamphlets in my medication I read ..."</p> <p>"... when I read the pamphlet it said something like fatal rash ... I was scared ..."</p> <p>"I read the leaflets, how to start the ... they say a whole lot of thing that you rally don't understand what they mean ..."</p>
Doctor	<p>"... doctor * he explained a lot to me ..."</p> <p>"I remember after that I came to ask him, because sometimes you hear, especially on TV a person talking about AZT. I don't know what that was all about. I don't know, even now I don't know much about the medication. But I keep from the other one. That just, this is the one I'm going to start you with. If we would experience into problems, I will change you from this on to that one ..."</p> <p>"... sometimes I just think maybe I should consult the doctor and ask is it possible for the HIV person to get pregnant and gave birth to the baby who is negative ... I'd rather not have a baby than that ..."</p> <p>"... most of the time I'm asking the doctor ... I'll phone him ..."</p> <p>"I want to have a child, I must consult my doctor, the doctor will tell me everything about pregnancy being HIV positive ... my age, ja I'm considering it ..."</p> <p>If in doubt you will check the trustworthiness of information you got at other sources, with your doctor.</p>
Expert	<p>"I have to learn more ... sometimes books are not that easily to ... people with knowledge are effective. But now it's hard to sit with a person with knowledge ..."</p> <p>"... if you read for yourself, and you are not able to understand it, and there is an expert, and they understand it, and they explain it to you in the laymen's terms that you are able to understand ..."</p>
Leaflets and booklets	<p>"... not even a thick book, something like a page. What you must do, because sometimes you're even scared, you can't ... and then you heard all these names, this CD4 count, viral load, and all these. And then sometimes it's like discouraging ..."</p>
Support group Helpline	<p>"No I don't have counselling group or people ... I know * have a ... helpline, something like that or counselling line. But I've never phoned them. The only time I phoned them was when I had the rash and I was complaining, now the funds are exhausted, what must I do? They were also nice ..."</p> <p>"I once phoned the help-line, they were not helpful at all ..."</p> <p>"... for me to phone, I'd rather use that services with I feel, when I need</p>



	<p>to find out this, this is happening to me now. Like I was concerned when the doctor gave me a prescription which only has AZT, and he didn't even explain it ..."</p> <p>"... you will meet different people, taking other medication than you are. You will get some new ideas from others ..."</p> <p>"... share ideas and then you get some new information from the other persons who are HIV positive ..."</p>
Pharmacist	<p>"... they give me another one, they say the are running out of this one. But hey say it work the same way as this one. So maybe if they can tell me what is happening ..."</p> <p>"... told you exactly how it should be dranked ... the ladies at the dispensary ..."</p> <p>"I said to my husband let's go to the pharmacist who gave me the medication ..."</p> <p>"I talked to the pharmacist, and he said no, don't reduce it ... continue with what your doctor has give you, and I said no-no, this is killing me ..."</p> <p>"I'd try to read the pamphlet ... the liver failure or kidney failure, and all that, that I was more worried ..."</p> <p>"... he said, OK, let me give you and then I'll phone them tomorrow ... he was giving me suggestions, basic things to try ... I had complaints that he could answer ...r"</p>
Medical aid support	<p>"I'll call ... first ... taught me about it but not all of it ..."</p> <p>"... the number is for 24 hours ... if anything I must speak to her ... my doctor there at the ... they made me a connection ..."</p> <p>"... it's only office hours ..."</p>
Informal	
Radio and television	<p>"Positive Talk, there's a lady ... who's been HIV positive about 15 years, she's the one, you know, who's educating the people about that. A lot of doctors phone there ..."</p> <p>"I've listen to Positive Talk on the radio ..."</p> <p>"... there is this program which I was watching on Sunday it's all about people who are HIV positive, but they talk. Maybe if they can have some sort of discussion, people being well informed about this disease, HIV and AIDS, you know. The medication and all. They mustn't trust whatever they are telling them, they must find out if it's true ... I think it's a lock of information ..."</p> <p>"... sometimes some other people, you hear it on the TV, they got</p>



	<p>some side effects, but they don't go and tell you I have side effects, they just say this medication is not good. But if you ask yourself why are the doctors giving us these medication, then you find out it's this"</p> <p>"I'm concerned about the virus, when they are talking about it on the TV, like I listen because it's part of my life now, so I have to know everything about it ..."</p> <p>"I once heard on TV because usually when they are talking, I always listen ... can affect your liver and all those things. But if I want to know, sometimes I ask my mom ... but the other one, they were saying some of the medication are toxic if you are taking it for longer periods ... make you scared ..."</p> <p>"... the information now, the things that we hear from other people and TV I stayed for so many years or ... they are going to give people who are, who've got AIDS, what at that stage, they are going to start the treatment there, by that time the only information ... you are HIV positive: Take treatment ..."</p> <p>"I'm very conscious of what is happening around me. I look, I listen to the radio, I read the papers, and I look at people. There are people that I know that have died from HIV but when I sit down and talk to people, they tell me the symptoms then I know this person that I know, that person was HIV ..."</p> <p>"... you find that maybe one goes there and then he goes and tells others this one will help you or what. And all people will go there. And when you got to these traditional healers, they don't ask money, maybe they say R10 or R20 a bottle and its herbs. So people go there if they want to be helped ..."</p> <p>"It was in one of the papers, they said that people who go there when they are really sick, then they got there during the day, then they'll prefer to go at night, being admitted there, because they are afraid people will know"</p>
Unspecified	
Printed literature	<p>"I had read around the question quite a lot ..."</p> <p>"I ... read a lot of books, but I can't get answers ..."</p> <p>"... you read a lot of books. You hear a lot of stories that people say that this person has been for 14 years on medication and is still fine. You know, things like that, and I said, why can't i? also at the church. They try to keep us positive ..."</p>
Internet	<p>"I think the websites are there, it's just a question of like the will, the curiosity to investigate further, and perhaps, like human beings, we have a tendency of wanting to be spoon fed and being directed ... where do I start ... and then you just procrastinate. And then I just goes by ... there is a lot of information floating around, we just don't know what is relevant and how to grab it ... quickly accessible ..."</p> <p>"I don't know whether I can trust or not, but I look out for information on the internet ... I look for information because I have access, I don't</p>



	<p>know about other people who don't have access ..."</p> <p>"... you are aware, but you kind of need the re-enforcement. You go to their website, you check the stuff. It's written in a user friendly language, everyone can understand it With information you are then able to make an informed decision ... at least it's like broadening your horizons if you know a lot more, because the moment we kind of put this under the carpet and you know ... the taboo just mound and build on ..."</p>
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3.7.7.4 Perception of level of knowledge

HIV-positive patients' perception of the information they receive varied greatly. A significant portion of the participants in a study by Horne, Cooper, Gellaitry, Hankins and Fisher (Gellaitry *et al.* 2005:374) was dissatisfied with the information that they received. They also found that patients who displayed concern regarding HIV and its treatment, were less satisfied with the information received.

"... I need more education about the ... I need to sit in the room with people that go through the same thing ..."

"I did not read a lot about treatment before ... I was really opened after ..."

"I didn't have a clue except for the general knowledge, I mean, you read and sometimes on TV ..."

"... more information as to how you can get resistant towards the drugs ... so I'm not clued up on that ... it's when you don't have information that it's very disappointing ..."

"I don't understand the composition of the actual medication."

"I only started to know more about it at a later stage that when your CD4 count is less than this and your ... you must go on treatment ..."

"... what I knew then was fine ..."

"... with this treatment I have no idea if this virus is still in my blood. I don't know, but I'm fine ..."

"I was so educated like a doctor ..."

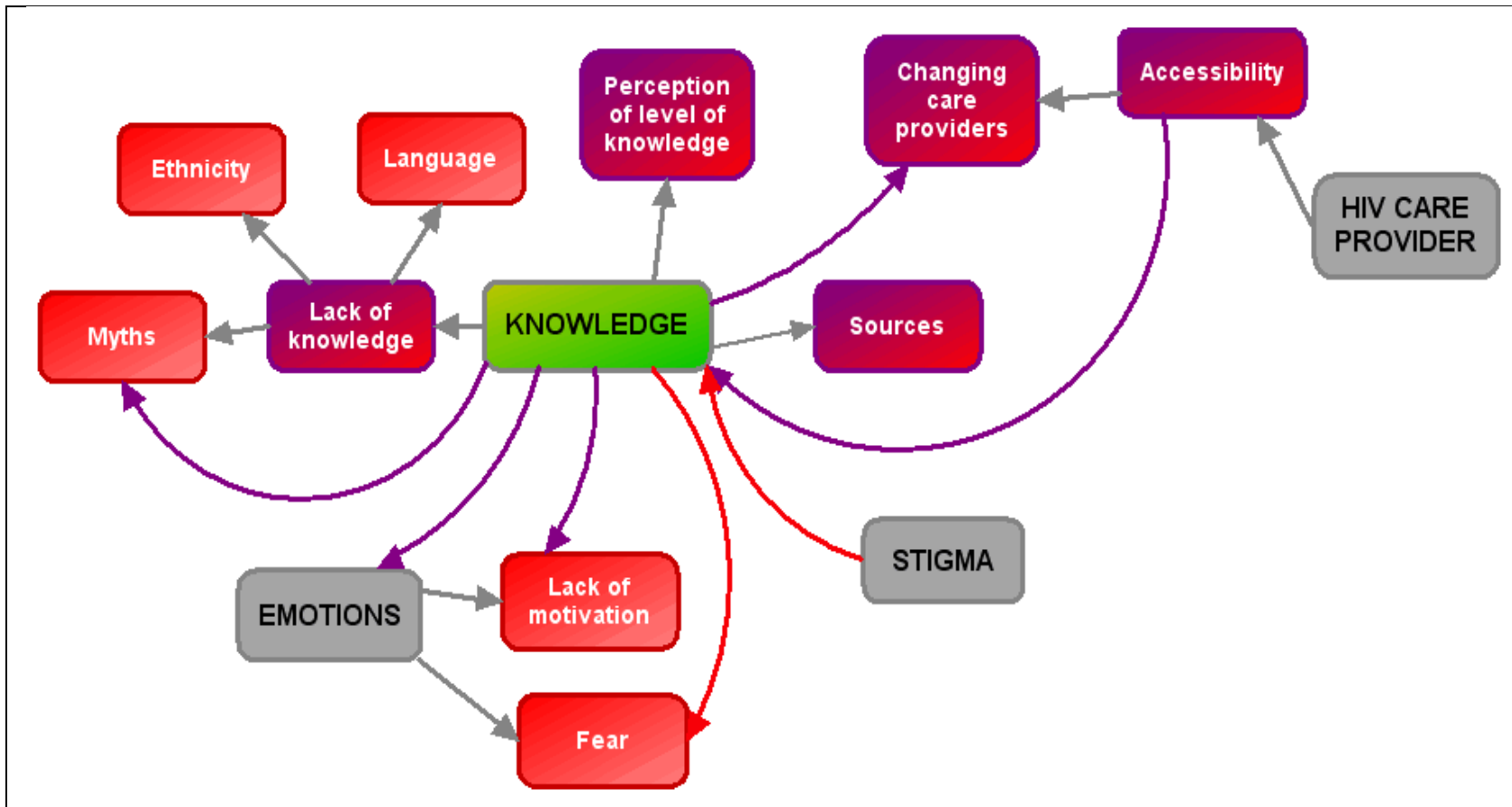


Figure 3.7.2 Aspects of knowledge that influenced or might influence adherence in context

3.7.8 Trust in antiretroviral therapy

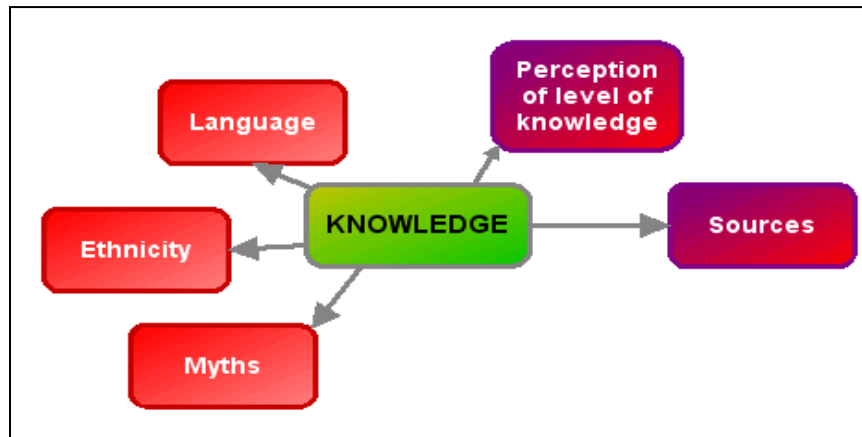


Figure 3.8.1 Aspects of therapy trust that influenced or might influence adherence

3.7.8.1 Desire to Live

Most participants expressed a desire to live. Their motivations differed, but ultimately it influenced their adherence positively. They also expressed confidence in the ability of antiretroviral drugs to buy them extra time as well as to keep them healthy for longer.

The desire to live might have been fuelled by other emotions and perceptions such as having minor children or a fear of death (Gebrekristos, Misana & Karim, 2005:774).

“I want to be on treatment because I want to live ...”

“I come to terms, I have it, but I want to live long ... I believe I live long ...”

“I need to live longer ... this motivate me ...”

“... let me rather take my medication and my vitamins. I'd rather reduce my vitamins. I'll take two out of the three, and some of them I'll have round about ten. But I made sure that I take my Combivir ...”

“... (*what is your priority?*) ... it will be the medication ...”

“I guess like anything you just find a way around I ...”

“I would try anything. You are really, you, you kind of find an excuse to get out of the meeting and then take the medication. Or perhaps, it’s just me, but that’s the way ...”

“... but I make sure I’m taking my medication ...”

“... if the lifestyle would demand a change or it’s making it difficult for me, I would, ja, I would ask for an alternative ...”

Most people are aware, through different sources, that western medicine claims an inability to cure HIV. According to Rowe *et al.* (2005:266) this knowledge can discourage people from accessing antiretroviral therapy or adequately adhering thereto.

In the light of the cost of antiretroviral therapy, and the effort some patients need to put into it to keep to their treatment, the knowledge that the medication cannot cure them, may be truly discouraging.

3.7.8.2 The power of the drugs

In a study by Wenger, Gifford, Liu, Chesney and Golin did an accurate perception of HIV and its treatment correlates well with adherence. Adherence was also higher among participants who perceived antiretroviral therapy as effective. Doubt towards the effectiveness of antiretroviral therapy, prevented 14% of patients from starting antiretroviral therapy. In contrast, 64% patients continued antiretroviral treatment because they believe that it combats HIV. In a study among Spanish speaking patients, 75% of the participants reported accepting antiretroviral therapy to be a necessary strategy to improve adherence (New York State Department of Health AIDS Institute, 2005; Broadhead, Heckathorn, Altice, Van Hulst, Carbone, Friedland, O’Connor & Selwyn, 2002:243; Murphy, Roberts, Hoffman, Molina & Lu, 2003:221; Wenger *et al.* 1999:abstract 981).

Identifying the need for antiretroviral therapy implies that a patient believes that the

medication can help in some way.

Most participants indicated that the drugs have a limited power but it is still important to prolong their lives.

“I know that the medication doesn’t heal. It only help ...”

“I think it doesn’t make it to grow. It become more, it lessen the ... because they told me I’m not healed, so I didn’t understand what is happening to the virus. Maybe it’s there but it’s limited ...”

“I know it’s not a cure, so I must follow whatever he tells me, because it’s not a cure. Make sure I don’t do the wrong thing ...”

“... take treatment and to live happily ... not taking treatment I think is strengthening the virus ...”

“I’m the one that’s taking medication ... I’m the one that is dealing with this ...”

“... it prolongs you life ... the medication will help to suppress and, ah, to avoid opportunistic infections, such as, you may then, live a kind of a longer and healthier life ... but I’m not very optimistic about living to old age ...”

“The medication weakens the virus ... if you stop, then it will grow again ...”

Drugs are important to re-establish health, but that there would also come a time when it will no longer be effective

“I must live for a longer time ... it doesn’t cure you, just to reduce that not to be high ... I think maybe if I can just drink them properly, then I’ll have the, my health will be better, but if I just keep on skipping them then I’ll become sick ... then I won’t survive ...”

“... it’s like other people got chronic illness, diabetes and all, high blood pressure ... they are on medication for the rest of their lives. So for me to be able, you know, to sustain the same and to be healthier, I must drink it, it must be like part of my life. So that’s why I don’t make a mistake not to drink it because in my mind if I don’t it means I put my own life in danger ...”

“... the medication is going to make your defense strong. It’s going to help you improve your immune system ... it’s going to prolong your live, it’s going to help to keep you healthier ...”

“... this treatment is not going to cure you. It’s going to give you extra time to, to live ... Eventually, I’ve got this time bomb, but rather than speeding it’s clock, rather delay it. That’s how I’m taking it ...”

“... because you know what, I was so thin. Look at me, I look healthy now. I recovered ...”

“... that medication helps me so much. So much. Because I was thin, thin. After the medication, I’m all right ...”

"I'm expecting an improvement ..."

"... she also tells me maybe I might be resistant to the drugs, so I was scared ..."

"... (*you are getting resistant to it and you have to change your medication*) ... I would not be that pessimistic ..."

"I don't really believe that they won't work, they reach a saturation point and they can't do what they are suppose to do ... they may not work as well as they did before and then they actually need to change them ..."

"... when you get resistant towards the antiretroviral drugs, it doesn't help anymore ..."

"... after a while then the medication will not help, the virus will get used to the medication ..."

Most participants, however, expressed the hope that there would always be other medication or treatment that they can utilize. One participant said that she would eventually die of AIDS because the drugs cannot kill it, but never expressed a fear that her drug options would be exhausted before that time comes.

This may be true when taken into account the continuous development of new antiretroviral drugs and classes (Nettles, 2005).

"I think there must be scientific reasons why the medication will be changed ... they change because it's not working, or perhaps it's responding, ja to a lifestyle. But I think it should be justifiable, medical reasons ..."

"... if I reacted, if it has any kind of negative effect. It is the doctor's expertise to decide what needs to be more or something better comes up, and that for me would be a valid reason for the doctor to change it ..."

"... if it's working don't tamper with it, but if it's not working, then try something else ..."

"... by the time I go on medication, I will have still another 20 more years. I have a six year old child, and sometimes I said if, with the grace of God, I can live for the next coming 20 years ..."

3.7.8.3 Monitoring treatment efficacy and detecting toxicity

Most participants indicated that it is necessary to monitor the efficacy of the antiretroviral drugs. This will also keep them up to date with their progress and can serve as motivation to continue with treatment.

Regular viral load measurements are currently used in antiretroviral therapy to determine treatment efficacy (Nettles, 2004).

“... it’s a way of monitoring what happen ... fortunately, my job is monitoring and evaluating, so it’s not a foreign concept for me ... it’s necessary ... it also keeps me on my toes ...”

“... mister * said to me I must come at least after every three months ... to take the blood and to give me my results ... to see if my life is well or what ... it’s important ...”

“... come back every three months for my blood tests and my physical check up ... I must test. I need to know what my status ... I have to know where am I. I don’t want to be surprised ...”

“... because he is monitoring my progress, then I’ll think maybe he see this is no longer fit for me and change it to the other ...”

” ... tell me if the medication is working or not ... the tests will tell you ...”

“... so I came back, came to see him, and you know, there was things, blood tests ... so he asked me, what have you done in the past weeks. And I told him ... because of that, now your ... other times I come he said your viral load is zero ... and my count also had increased, but at that time he could show that something happened, because my viral load increased ...”

“... he also gives me courage sometimes because my CD4 levels are coming OK ...”

“... when I came to check the blood tests with doctor * then I, I could see that they did work ...”

“... the previous test shattered me ... he said, your CD4 count has gone down. And I was like ‘What?!’ ... then I discovered that my CD4 count was like 200 I think ... I don’t want to see my CD4 count there ... I didn’t expect it to tell me that I have got down a hundred within a month ... this test that I’m going to take now I’m looking forward to it ...”

3.7.8.4 Antiretroviral therapy and alternative therapies

Participants held different opinions on the importance of alternative therapies and its relation to antiretroviral therapy (See 3.7.1.2).

“I won’t place a lot of value on antiretrovirals, by themselves. Or a lot of value on hm, like a diet, by itself, as a stand alone thing. There has to be perhaps the antiretrovirals, the diet, everything together ...”

“I take them as supplements ... it also depend if they are clashing with your medication ... maybe if it’s something that’s been researched in the market, and I know more about it ...”

“... ja, any medication have to be complimentary if the composition of one negate the other, then it’s problematic ...”

“I don’t exercise ...”

“... you can live longer provided you live like this, that you change your lifestyle ...”

“As long as I take care of myself, eat properly take care of the stress, ja the I can live for long ...”

“I try to take care of myself although I'm not 100% right ...”

“I've never smoked ... you have to try to take measures, preventative measures for your health ... anti-oxidants vitamins in my system that can help me ...”

“I don't drink.”

“... by all means to minimize stress and ... as much as possible the fact that I have some level of depression at work and I got seriously, seriously ill ... I think that state, emotional state made things to be worse. Maybe if I was OK emotionally, I could still maintain it at a certain level. So I always think of that experience and I don't want to go back there ...”

“I take good care of my health ... I don't do drugs, I don't drink liquor, I don't do anything that would hamper me with my health ... I'd make sure I eat healthy, I'd make sure id o things, you know, my life is, I mean, coordinated in the right ...”

“I used to take many vitamins, about seventeen”

“... it depends what I'm eating, what environment I find myself in ...”

“... the things about immune boosters, calories, I don't know anything, I admit, I'm not really sold, so I'm not really going to read a lot about that. About a healthy lifestyle, ja, I do read, and I also think it influences ... to an extent ... kind of a holistic approach, but as such I'll be looking at lifestyle, positive outlook and the antiretrovirals, but I think the antiretrovirals has a kind of a bigger role to play ...”

“Advance Transfer factor ... my CD4 count as I told you, it improved quite a lot. From 200 to 509 ... I'm actually attributing all this to that ...”

“... my CD4 count was very good. And through a lot of stress and everything it went down ...”

According to Rabkin and Chesney (1998:[2]) patients' beliefs, knowledge and expectations regarding antiretroviral therapy influence their preparedness to commence treatment. The opinions of family and friends may also influence their decisions regarding treatment. A lack of belief often leads to treatment refusal. However, some patients often do not refuse treatment outright; negligence on the part of the health care provider to assess a patient's readiness and willingness to commence treatment, may lead to inadequate adherence.

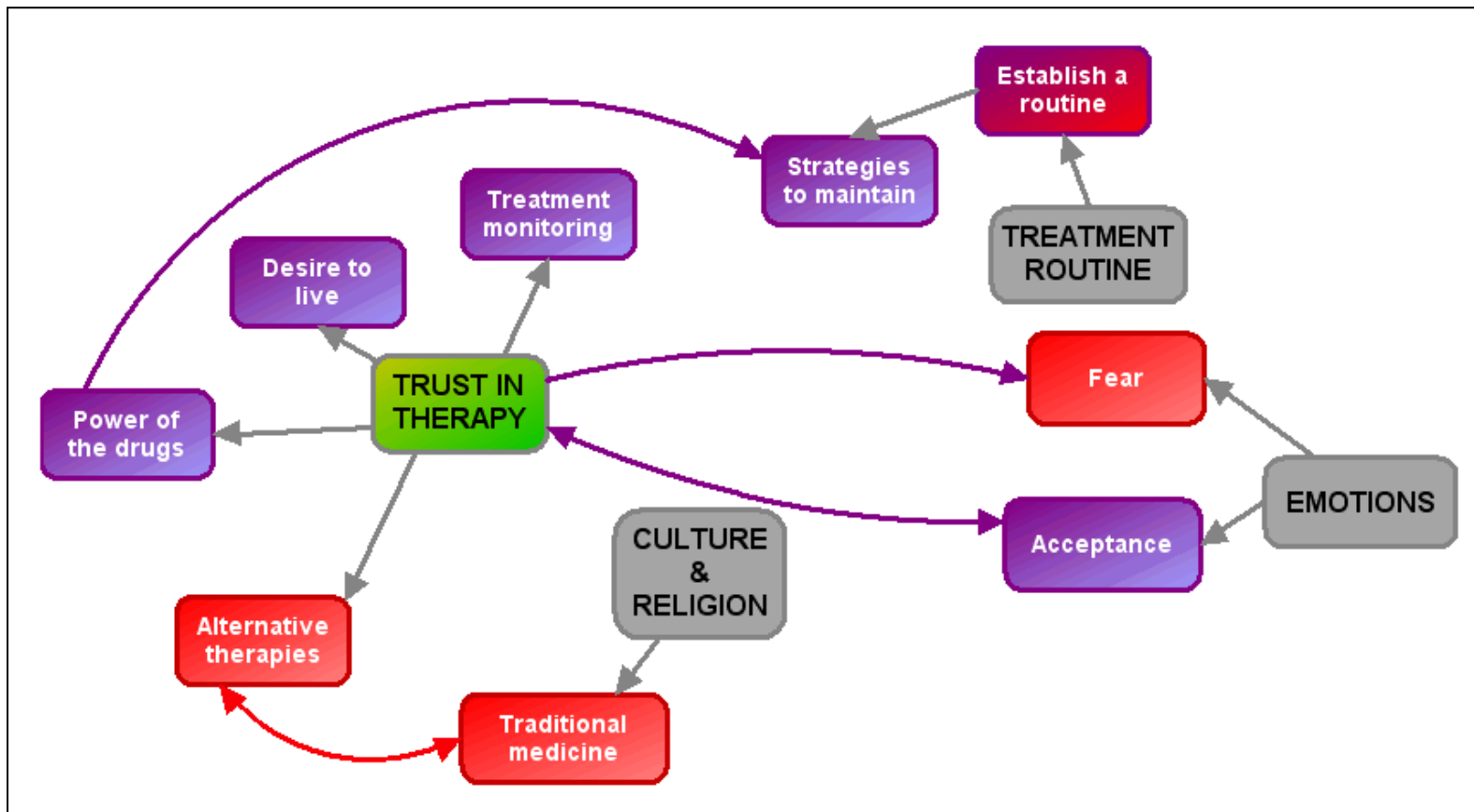


Figure 3.8.2 Aspects of therapy trust that influenced or might influence adherence in context

3.7.9 The influence of stigma

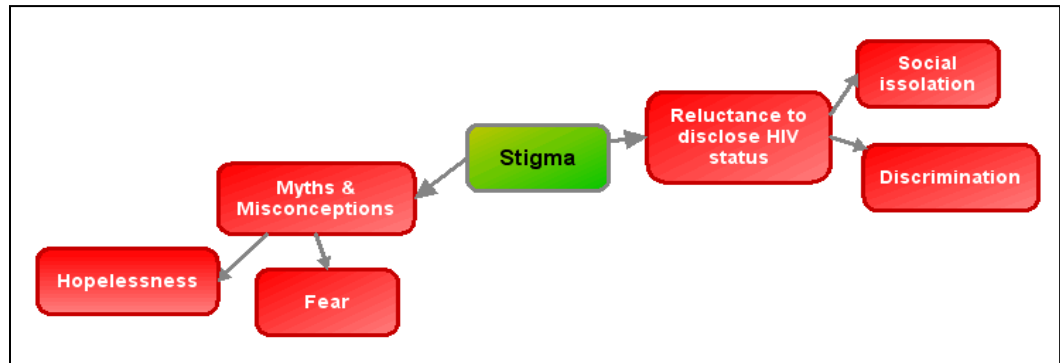


Figure 3.9.1 Aspects of stigma that impacted or might impact on adherence

3.7.9.1 Myths and misconceptions

Due to the prolonged debate regarding the relation between HIV and AIDS, mainly fuelled by the debate on HIV in parliament, many myths and misconceptions regarding the disease exist.

A national internet based survey regarding the correlation between HIV related knowledge and stigma had been completed in the United States of America. Stigmatized responses by participants regarding the transmission of HIV were 25% for those who were misinformed, compared to the 14% for the correctly informed (CDC, 2000).

“... even when he is married he will say it's not me, it's you. He will blame her ... *(one lady told me that someone she know who is HIV positive was banned from her own home by her husband)* ... Ja, even if he is also positive ...”

“... the likelihood of that person being chased away and the stigma would fall on her ... it's always assumed that the problem lies with the woman ...”

One of the most prominent misconceptions is that HIV is a death sentence. And with parliament putting public antiretroviral therapy off for years, it was in fact the case for many patients.



“... with HIV, everybody has just has put it under the catel. It’s a death sentence. It’s a dirty disease. They don’t actually think of HIV, just thinking of AIDS. Oh, she’s got AIDS. She’s going to die. The people are the ones that are killing other people. Because immediately somebody’s got HIV, then all they think about is dying ...”

“... the perception that we may have about the people with HIV, once the person is starting to check the CD4 count and other things, if mean they are sick ...”

“... immediately someone loses weight these days, you only think of AIDS ...”

“HIV is not really a death sentence ... even you who are healthy, you can die even now and I can live longer than you ...”

One participant indicated that people would rather kill themselves than live with the shame attached to HIV.

“... there are still those people who think that if I’m diagnosed HIV positive, I’d rather kill myself ...”

The stigma surrounding HIV often labels women as unworthy, immoral and devalue them as mothers, sisters and wives. Women also fear losing their children when admitting or proclaiming they are HIV positive. These beliefs prevent them from seeking medical care and contribute to inadequate adherence (Trzynka & Erlen, 2004:[7]).

Some participants emphasised the idea that HIV is a disease that happens to other people, people who live on the streets and are prostitutes, not normal people like them. Many people can therefore distance themselves emotionally from someone who is HIV positive with the attitude ‘that you get what you deserve. I’m not like you, seeking for it’.

“... you’ll find that ... especially people are still talking about HIV/AIDS withdraw ... I won’t get it, it’s not for me ... it’s only for these people who live the street life ...”

Because of these myths, people consequently developed several fears and assumptions regarding HIV and its impact on people’s lives.

“... it can not hamper a relationship, it cannot erase memories, it can not do anything. But the only enemy that we have within this disease is ourselves. It’s the disease actually itself that’s the enemy. But I can not destroy you completely. It cannot stop you loving people and it can not stop you remembering things. It can not take away anything from your. It’s limited ...”

Most participants tried to ignore these unkind remarks and actions people displayed borne out of ignorance regarding HIV and AIDS.

“I don’t feel that I need to explain and apologize to other people ...”

“... you get pockets in the society that’s friendly but it’s still not the norm. You ignore unkind comments. You don’t try to defend the issue as you don’t have the time to try and convince people about something they are not able to understand. Defending the issue might also put yourself in jeopardy ...”

“... there are acceptance ... intricately enwound with a human being ... just in the same way as we deal with a divorce ... that kind of acceptance ...”

3.7.9.2 Reluctance to disclose HIV status

In a Botswana study, stigma proved to be a comprehensive factor in the lives of people affected and infected with HIV. Broken marriages and relationships, rejection by family and friends, isolation by the community and loss of employment are but some of the behaviours that HIV positive people need to endure when they disclose their status. In fear of the consequences of stigma, 69% of these participants decided not to disclose their HIV status to family members, while 94% kept it a secret from the community (Weiser *et al.* 2003:285).

People living with HIV, and their families, tend to keep quiet about the diagnosis, for fear of rejection and social isolation. The tentacles of stigma is not limited only to the person who is HIV positive, but also affects the lives of the family and even friends.

“... also the issue of fear to be judged as an outcast ... something less than human ...”

“I don’t want people to start being mean to me because of my, because as much as, people talk about the illness openly, but hey haven’t actually accepted it. So I think what make the situation, what normally makes ... especially people dying very ill, is the fact that they get to be rejected ...”



“... maybe if I can tell my friends, then they will start to isolate me ...”

“... no, I'm still afraid. You know what, the people, when you are HIV positive, they are afraid of you, they make funny remarks on you. So I don't want to hurt myself ...”

“... they still treat it as something ... with stigma ...”

“... ja, it's bothered too much ... because other people, if you're HIV positive, they don't think you are a person ...”

“... it's a something that you really don't talk about, and there is still that taboo and you don't feel you kind of feel people will be judgemental if you open yourself up. I've never tried it, but if I opened myself up and say I'm HIV positive, and ... because I'm like so worried about how are they going to react. So you just kind of shut yourself up ...”

“I don't know if it's there in the white culture, but you know, the black culture, well from my experiences it is still very taboo ...”

“... they call it the three ... they call it the three little words, for HIV ... they don't mention ...”

“... with the black culture, they even hide even more, they tell you that person was given muti ...”

Because of a fear of discrimination and isolation most people tend to keep their HIV status to themselves or only disclose it to a few people whom they trust. This was also the case in a study conducted by Rowe *et al.* (2000:265), where five out of six participants disclosed their HIV status to someone who was able to provide them with financial and emotional support. Disclosure was however limited for fear of isolation and stigmatization.

“... since I was diagnosed HIV positive, I haven't disclosed it to many people ...”

“... my mom is the only person that knows ...”

“... it's only me and my husband and doctor ...”

” ... five people who know about my situation ...”

This is, alas, also the case when people are dealing with health care professionals. Many HIV positive people do not inform a stand-in doctor of their HIV status; in particular that they are on antiretroviral therapy. This tendency can cause drug-to-drug interactions between the medication prescribed by the doctor or pharmacist, and

the antiretroviral drugs. A participant shared that she was reluctant to question her doctor regarding treatment the first time that she went to see him. She felt that she did not have a relationship with him and did not know him well enough.

“... the first time, even first time going to see the doctor. Now I feel I’m comfortable, and I hope, maybe as time goes on, with my status as well ...”

“... after a year I come to terms with it, you know, it doesn’t worry me anymore. Like for instance, in the past if you go for, to the doctor, maybe for flu, they would ask you are you taking any form of medication, I’d say no. Because if they asked me what medication, I’m supposed to tell, and it was this medication ...”

“... (*can you get your antiretrovirals also from the pharmacy, the medical aid pharmacy?*) ... no, I would never ... my husband doesn’t want to, he work there. And I understand him. You know. He doesn’t want to be labelled as your wife is HIV positive. So my, any other medication I take there, but my ARV’s I take from the pharmacy ...”

People are also reluctant to ask for information regarding HIV and its treatment, as they fear that they may be labeled as being HIV positive themselves. This is true for people who are HIV positive as well as people who are affected by the disease. People then tend to turn to what they know from experience, and to traditional medicine and myths. They also hear about antiretroviral therapy from other people who might not have had the correct information, and the stigma of antiretroviral therapy is thus spread further.

“... especially with us blacks, OK, they will know maybe within the family that you are HIV positive, but still they won’t go out and find information, they will hide that you are sick ... so the information they got is like maybe in the taxis people talk, and then they hear that ... and people will go there ...”

Some participants shared that they would like to disclose their status, but that they are afraid of the consequences.

“... you don’t want people to know ... I look forward to the day when this can be really open ...”

“I’m not ready to talk about myself. I think that is very confidential. The medication itself is very confidential ...”

“I don’t know because I’m not still bold enough to tell others that I’m HIV positive ... I just told them, I just get them, you know, one-on-one ...”



“... step out and say I'm HIV positive ... No, I'm not scared of that one ...”

“I can't tell anybody at work, I haven't tell anyone, except the guy who used to fly ... it help if somebody leads the way ...”

“I know they'll be shocked because of how they related to me ... they'll more likely not to believe ...”

One participant in particular mentioned that it was not her decision alone, but that she has to first discuss it with her husband and secondly, that she will have to educate her children about HIV and her being HIV positive, before she can take such a step.

“I had to consult first ... my husband and my kids also ... if I choose to go that route I'll have to teach and educate. Kids this is my situation. Your mom is HIV positive. Kids are going to fear. And they ever oh, our mom is dying now ...”

Several participants also indicated that they would rather get help from a white person than a black person, as a white person still treats a patient with respect.

“... the white person doesn't like the black person. They don't decrease a person. So the white ones I have no problem. If I give them the script, they give me my medication. They didn't question me about anything ...”

It can be acceptable if someone else than the people they had specifically disclosed to know about their HIV status, as long as they understand and treat them with respect.

This mainly applies to medical aid and laboratory personnel.

“I'll be cross ... because I don't think I want other people to know about my situation ... it would be fine ... as long as they give you an idea of who they are and where do they fit into the picture ...”

Another participant, however, was opposed to this idea.

“I wouldn't approve if the receptionist knows about this. I wouldn't feel right. You know, I wouldn't like it ...”

One participant indicated that the stigma and myths surrounding HIV originate from a lack of knowledge and understanding of the issue and that people who are closely

related to someone having HIV are more tolerant.

“... those people, I don't know how they are going to react ... (*fear of rejection?*) ... ja, that would be a problem ... the way they talk sometimes ... people who got this, I don't want anything to do with them. I don't want someone to come close to me ... sometimes it make me sad, and then I realised that people you know, they don't understand ... after some time this one now can relate, because there is one in the family ...”

“... sometimes when they talk, the things is, you can hear from their talk that ... you heard, so-and-so is sick. And they are doctors, but sometimes ... they don't understand ...”

“I've decided not to disclose ... they think if you sit like this the virus can maybe to fly ...”

“... but the other family members ... according to them, there is no one in their family ... who is HIV positive. They still take it as ... the comments that will come ... it's not easy for me to disclose to them ... they haven't got enough information. I would try and show them the importance of everything and people who are HIV positive and to give them more knowledge, but at the moment, they are still, like it will never come to them ...”

3.7.9.2.1 Impact on treatment

Although none of the participants indicated that keeping their treatment a secret to family and friends impacted on their adherence, there were concerns that keeping treatment a secret to a partner may interfere with adherence.

This is consistent with the findings of Weiser *et al.* (2003: 285) who found that only 15% of participants indicated that stigma interfered with their adherence to antiretroviral therapy. This factor was prominent amongst participants who were not able to take their medication at home or at work for fear that they may be discovered to be HIV positive. This is not only applicable to drinking the medication, but also to visiting the healthcare provider and collecting medication.

However, in a study conducted by Durante *et al.* (2003:108-9) 75% of patients living with other HIV positive people were adherent in comparison with 25% inadequate adherence in this group. Furthermore, adherence amongst HIV positive people living with others who do not know that they are HIV positive, were 20% lower than when their status were known.

Most participants in the study removed the labels from their medicine containers, or put the medicine in other containers. They also store it in a place out of sight of visitors and family members, in particular children.

“... when I have friends staying over ... I always find the coolest place in my bedroom, to keep it ... I take of the label, and I just have an empty, what’s it called, an empty ... a clean container ...”

“... my medication is in my shelf, so I know they are coming, I just remove it ...”

“I couldn’t keep it in the fridge because we, it’s only me and my husband who knows our status. So our children don’t know ...”

Other participants kept drinking their medication in the presence of other people, but when asked about it, they pretended it to be something else, for instance vitamins or medication for some chronic disease like hypertension.

“But I’m used to be taking vitamins, so it’s not a big deal ...”

“I put it in unlabeled containers ...”

“... my sister, and she’ll see me taking the medication, I don’t tell her, but I will then use an excuse and lie ... I don’t even hide it. If they see I’m taking tablets they just assume it’s for my blood pressure ...”

“I see my husband he takes his tablets and then he puts them on the table so that he doesn’t forget, while he’s watching TV. But the moment somebody kind of say, the bell rings, I see the first thing he does is he pulls them of and the puts them somewhere, he puts them in his pocket ...”

One participant in particular mentioned that she would not want to disclose her HIV status to her family, not because she fears rejection, but because she suspects that they would become over protective.

“... how to deal with HIV when you are on outreaching ... when they saw me there they didn’t touch the stuff. And I laughed at them and I said you shouldn’t. I would NOT feel offended ... these people they don’t know me. They don’t know that I’m, I’m HIV positive ... probably they felt I’d feel out of place ...”

“... it has more to do with sparing them so they don’t have to decide how they treat me. For me it wouldn’t matter how they treat me ...”

“... within my immediate family, only one person knows ... not out of fear because they would reject me or that, no, it’s more, out of, if you like, I don’t want to say protecting them ... she would



end up being too protective which I would find smothering ... it would be problematic, because it would be a constant reminder. And as much as I know, I don't want to be reminded every day ..."

One participant felt some reluctance to go to the doctor because maybe somebody will know that she goes there for HIV treatment, although he specializes in infectious diseases and internal medicine, and see a lot of other patients as well.

"... if people see me going there, what are their assumptions when they see me going there? But at the end of the day, it does not bother me because I don't know those people, it doesn't get to me. It doesn't bother me, like anything, if you go to a doctor, there is something wrong with you. It could be your pancreas, it could be a headache, it could be anything ..."

"I think that's kind of something that's at the back of your mind because of the stigma that's still attached ..."

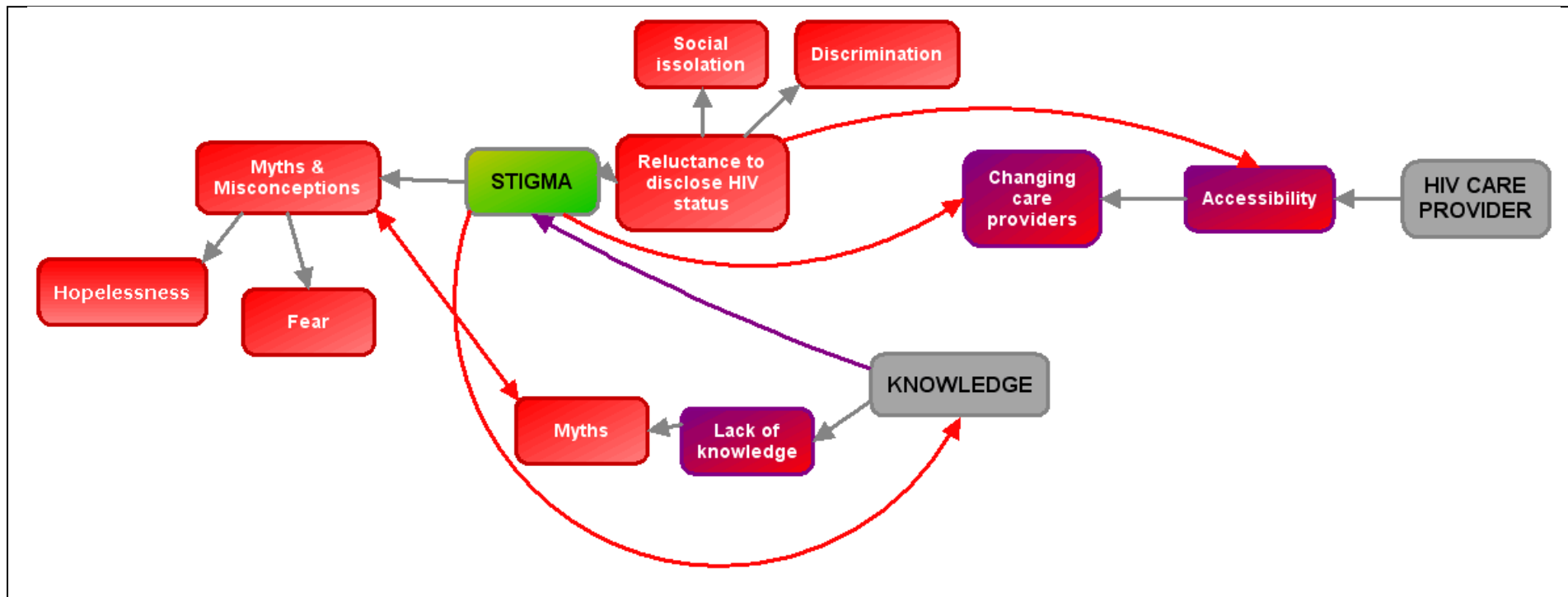


Figure 3.9.2 Aspects of stigma that influenced or might influence adherence in context

3.7.10 Support

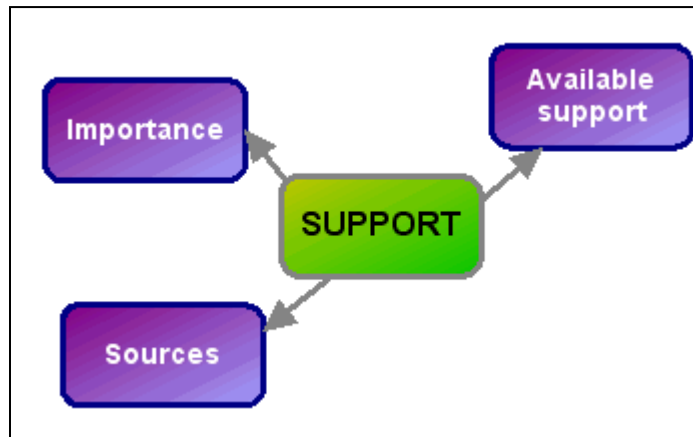


Figure 3.10.1 Aspects of support that influenced or might influence adherence

Participants in this study utilized several different kinds of support. Participants in a longterm relationship or marriage acquired their support mostly from their partners. Parents were listed as a main source of support by participants who have either lost their partner or who did not have a partner at the time of data collection. Friends and family who were not aware of the participants HIV status, were also mentioned as sources of indirect support. For the duration of the study, no participant indicated that her adherence was adversely affected by the loss or decrease in support she experienced, although no participant has ever been left without any support system for a period of time. Antiretroviral therapy was more important to most participants than being supported or not.

In this study support, perceptiveness and feeling valued had been a positive influence on adherence, but a lack thereof did not influence adherence adversely.

3.7.10.1 Perception of available support

Two participants expressed concern that the support they have received while they were still healthy, may differ from the support that they would receive once they fell ill

or become bedridden. At the time of data collection one participant also received support from people who do not know that she is HIV positive. These people may withdraw their support once her diagnosis becomes known.

“So I’m thinking what will this persons be like if you undergo some difficulty”

“... there is a big difference between general support and HIV related support, I think so, I don’t know ...”

“I haven’t been sick you know, and that will be the time when you see if people are helping you, supporting you. I was forever like this, not wanting to feel bad, it’s only when I got the results, first time you know, I ten to ... but after that, I was not sick ...”

3.7.10.2 Importance of support

Several participants indicated that it is important to have a support system.

According to literature, there is a positive association between social support and the level of adherence accomplished by a patient. Rowe *et al.* (2005:265-6) observed that a lack of social and family support affects adherence unfavorably while Douglass *et al.* (2003:[11]) identified a lack of hope and HIV-specific emotional and tangible support as barriers to adherence.

In the presence of poor disease and treatment literacy, support can act as a mediating factor to achieve adequate adherence (Lee *et al.* 2004:[5]).

“... you can get whatever pills are out there, but if emotionally you are not OK, if you don’t have a support system, it won’t work ...”

“... initially he didn’t believe me ... and then gradually he believed me ... it doesn’t bother me ... I couldn’t believe it. You must also be positive, you can’t just take it like this ... I didn’t believe him, it was like nothing has happened. This one must be positive ... they take blood tests and it’s still being negative. So that’s when I said, if you want to marry me being like this, it’s fine ... it’s your choice. And he’s supporting me 10 ...1”

“... you need to identify somebody out there ... because if you don’t have a person to talk to, this thing will become worse, it will stress you more. And stress is one thing that you must avoid at all cost ...”

“... to give them some hope ...”

“... bring back ... that confidence that has died and the self esteem that has died within them, and tried to get them out of this thing that the disease has been stigmatised and the sense that it is deadly ...”

3.7.10.3 Sources of treatment support

In a study among Spanish speaking HIV positive patients, the following sources of social support were identified:

- Support from partner (22%)
- Support from child (9%)
- Support from health care provider (9%)

Support was mainly in the form of a verbal reminder (38%) (Murphy *et al.* 2003:222).

3.7.10.3.1 Formal sources

Most participants make use of a medication deliverer. These systems work on a calendar schedule and deliver medication strictly every 30 days. These systems are convenient in the sense that it will deliver the medication at a venue of the patient's choice. Medication is wrapped in a container with only the patient's identification detail on the outside. This enhances confidentiality. Patients are reminded of an upcoming delivery and the delivery address is confirmed before hand. Patients therefore do not need to remember to refill a prescription. For example when a patient's medication is for instance delivered at the health care facility, the patient receives a SMS to announce the delivery.

“... pharmacy delivery system ... I think that would be fine because then I don't have to struggle ...”

“They are delivering everything here ...”

“... for me I thought it would be just convenient because I can get it up here ...”

“... for me it's easier because they bring it at work ...”

“The medication comes through. It’s delivered at the doctor’s place ...”

“... sometimes they deliver it at my work, sometimes they deliver it at my place ... I think it’s much easier when it’s delivered ...”

“... they are sending me a message through an SMS ...”

“... they remind me ...”

Some participants felt it would be difficult if they have to collect their medication from a pharmacy when provided with a script. They will feel exposed and scared. Others, however, did it before and experienced no trouble.

“... for the first time I was collecting it ... and it was OK ...”

“... some other guy ... he started asking why are you taking all this medication?”

The relationship one particular participant had with her pharmacist may have been a decisive factor when at one stage she needed to refill a prescription, but found out that her medical aid was exhausted at the time. Nonetheless, her pharmacist provided her with the medication.

Patients’ support services need to be linked with their regular medical care. This entails a mix of adherence advice, individualized counseling and support groups. All these services should be rendered by trained professionals and adapted towards patients’ individual needs. Of all suggested interventions proved direct intervention to help everybody regardless of individual, social and economic differences (Guarinieri & the ICoNA Community Advisory Board, 2002:[2]).

Most of the medical aids and HIV benefit administrators bring patients in contact with a professional support person who can help them solve medical aid and treatment related queries.

“... they gave me someone to communicate with ... regarding the medication and the medical aid ... make sure that you don’t get your medication a month late ... what if I start to have a problem and I dial the line and she’s no longer there?”



“... she give me hers, so I'll phone on Monday ...”

“... delivery problem ... it's solved ...”

“...everything will be fine because mister ... he follows every step ...”

“I was a little annoyed with them because I felt they could at least have phoned me ... notify me that they have a problem with my medical aid ... or that there is a problem so we are not doing the delivery ...”

“I don't know ... because on the same day, there's another lady, she phoned me ... so now they are going to send me those both medications. But she didn't, she sent only the Combivir. I don't know, that is a problem ...”

“... anything, even for my blood tests also, she remind me, and for my prescription, because I think it is for 6 months, when it's about to finish, then she phone me and tell met that I must get another prescription from the doctor ...”

“... when you had problems with first the medication that was not delivered, was there somebody you could phone to help you sort it out? ... no, it was not easy ... maybe if Felicia were there ...”

“... there's another girl, I don't know her, we speak on the phone, doctor *, I don't know her, we speak a lot about this ...”

“... the medical aid, they've got a lady who always phone me, she wants to find out how am I doing, am I OK ... once a month or maybe once every second month, am I OK, drinking my medication, do I have other questions?”

“... the only time that I'm phoning is when I'm feeling something ...”

“... that lady always keep on phoning me and say that it doesn't mean that when you are OK you can stop, you must always take your medication ...”

“... the first time she phoned, I was concerned, who is this person? And then she explained to me that they are from the medical aid, so they are phoning the people and trying to make sure if there is anything I don't understand ... I must phone them and ask them. They are there for us to help us. And then firstly I was like ... and then she phone again, and after that I started to relax ...”

Bodenlos, Grothe, Kendra, Whitehead, Copeland and Brantley (2004:717-719) identified a positive correlation between professionalism, emotional support by the health care provider, and patients satisfaction. As patient satisfaction with medical care is positively related to adherence, both professionalism and emotional support should then also facilitate adherence.

Most participants indicated that their primary HIV care provider was their main source of treatment support and information.

"I've got from doctor ... The support I've got and the knowledge about this, I've got it from her ..."

"... marvelous, he would really, really make me to be strong to understand everything. He was superb ..."

"... the previous doctor I was at teaches me a lot about this disease. I feel I know a lot ..."

"... even the information and the ... sort of counseling I got from the first doctor, he told enough maybe ..."

"I think he told me more ..."

According to one participant, healthcare personnel tend to provide information and guidance regarding the basics of HIV infection and its treatment, but then withhold further information. She explained that she would welcome a continued HIV education process especially regarding issues not often discussed in general HIV literature.

"... just keep me informed if something happen in their field ... they tell us eat healthy food and do exercise and all those things, they do. But sometimes they can even go further as to why it is that you are not supposed to do ..."

One participant felt that doctors could be more involved in their patients' care and wellbeing.

"... the doctor ... maybe if he can contact me once a month, or just to find out how am I doing ... am I OK, am I taking my medication ..."

Other participants who previously encountered such care from their primary HIV care provider, expressed satisfaction with such a level of care.

"although on the phone ... don't forget, six months is over, come let's take your ..."

"they will phone me, I hope today you are coming to fetch your medication"

Patients often share their difficulties regarding their treatment with their primary HIV

care provider and usually expect guidance. One participant indicated that her doctor's inability to help her with a treatment related problem left her helpless.

"... when I travel overseas, I always have a difficulty either with the time frames ... I pointed it out to doctor * and I said how do I do it? ... oh, just remember ..."

Most participants, however, indicated that their primary HIV care provider was willing to help them with problems regarding their treatment.

"I looked at my medication and I saw it was not enough for three weeks. I was leaving for three weeks. He made ... and pains that I get them ..."

"... if somebody would discuss a prescription ... it would help ... work it out with your schedule ..."

"... the first doctor that I actually discussed it with me. This is wrong, this is wrong, why is it going down. He said to me, you are not taking your treatment ... and I was what have I done ..."

"... after I came to see the doctor and I know exactly where I stood with my health ..."

3.7.10.3.2 Informal sources

In this study, eight of the participants had children. They indicated through their comments that they wanted to protect their children physically and emotionally. This protective urge implied that they need to stay alive for at least the time it would take their children to become independent. In this study it served as a major source of treatment and adherence motivation.

"I love them so much, and I don't want them to, you know, to live and suffer, without a mother ... in most cases the mother is everything to the child ..."

"... who's going to look after my kids?"

"I'm very jealous when it comes to my children. My kids are my kids. And my kids are not crippled they are everything ... to me. You know, I don't want anyone to cripple my child ... my children. I don't want anyone to cripple MY children, and that is the thing that keeps me going. So I will never allow myself to die ..."

"I think in my case, if my kidneys are going to fail, I don't know if it is kidney or liver, it's going to fail one day ... I thought, at least I will see him growing and try and adjust to other people. At that time he was totally dependent but if I die tomorrow, I don't know what's going to happen. I always think of my child, my child ..."

"I would never take my life. I love my child. I don't want to put him through hell ... help me to be

strong, just give me more years ... I need to be here for this child ...”

Most participants therefore indicated that they are taking antiretroviral therapy either solely or partly because of their children.

“... whatever I do, I'm not doing it for myself, I'm doing it for my kids ...”

“I'm not doing this for myself alone ...”

“... yes, partly for her and partly for me. Because I definitely want to see her grow, it would be, you know, I don't want her to be motherless. That's for sure, so if I'm not cautious, it can lead to a situation whereby maybe I die before time ...”

“... it was for him, and partly for myself, but now, apart from him, there is still that life ...”

“... if I didn't have a child I still would have a life ... so if I want to live, and obviously there are things that I want to achieve, and if I'm careless about taking my medication, it would be, I'm putting my own life in danger. But the fact that I've got a child now it makes it even stronger ... so I'm not doing it for her, it's me first and then he ...”

One participant was on antiretroviral therapy when she fell pregnant. She then stopped one of the drugs on recommendation of the doctor, because of its known teratogenic effects.

“I stopped Stocrin because I'm pregnant.”

Another participant said that she preferred not to use antiretroviral therapy during her pregnancy because of fear that it may harm her baby. She, however, agreed to the other advice, namely caesarean section and not to breast-feed the baby.

“... we did the best we can ... to protect the baby ...”

“... then I'm pregnant, I can not, I don't want to drug myself ...”

Another participant started with antiretroviral therapy solely for the purpose of prevention of mother-to-child transmission of HIV. She will discontinue antiretroviral therapy as soon as the baby has been born, as her immune status is still not



warranting treatment.

"I also think if I can go for a caesarean and I'm not breastfeeding, I know it will help ..."

"I haven't been to counseling because I feel that at the moment, this child is more important ..."

"I take it for the baby now, I don't need it ..."

When a partner is either involved in a patient's treatment, or is himself using treatment, it creates a feeling of belonging. In the SMART couples program, Remien, Stirrat, Dolezal, Dognin, Wagner, Carballo-Diequez, El-Bassel and Jung (2005:807-814) found that involving a HIV negative partner in the education and preparation for treatment, usually reserved only for the patient, significantly improved adherence.

Adherence was, however, still suboptimal and declined over time.

"... you kind of look out for each other. In a very veiled way ..."

"... him remind me was an indication of him being comfortable with this. And think it would have been quite problematic if I had to take this without him knowing. It was then always as if I had to play hide and seek ... and I think that would have interfere with my adherence ..."

"... it's important that he understands for instance when I come and see the doctor it's not because I'm sick ..."

"... "if he tests positive I'd make sure he gets the same treatment as me, so that he can live longer ..."

Another participant however indicated that if her partner was also HIV positive and on treatment, she would felt burdened as she would feel obliged to worry about him and his health as well.

Wagner (2002:605) found that social support can add stressors that may interfere with adequate adherence, by adding stressors, responsibilities and extra burdens to a patient's life.

Most participants indicated that their partners or husbands played an important role in supporting their treatment.



Social assistance can play a major role when commencing antiretroviral therapy. Having a person who can provide reminders, be it in a social or professional relation, can prove valuable. Some patients have their children to help them remember while some children are reminded by their mothers (Rabkin & Chesney, 1998:[2]).

Two participants indicated that their children help them to remember taking their medication, although they are not aware what it is for.

“... when I forgot, she'll ask me 'mommy, have you take your pills today? No you can't leave it out ...”

“... she knows I'm on treatment. She doesn't know what this treatment is all about ... I've made her to know ... I wanted her to be able to help me, because I don't have, you know, family support around me. It's only the two of us. So if I get sick, at least she must start getting to know my mother have to drink ... sometimes she even reminds me 'mommy, have you taken the medication?’”

Other participants indicated that their parents or one of their parents are a great support to them

“... my parents will ...”

“I stay alone ... I think when the situation were to arise I'm sure a member of the family can arrange to come up ...”

“... for three to six months he was my reminder ...”

“... he's like a spy ...”

“... every two weeks he call me ... he wants to know about my situation, and then about the medication ... they check on me, every two weeks they call on me ... to find how I was doing with medication. Am I taking it all right or what?”

“I feel you are just reminding me, you are helping me, because maybe I might forger, or something happen and then I totally forget, or other people, even if you are old, you might take it lightly and say no ... I think it helps ...”

3.7.10.4 Sources of social and emotional support

3.7.10.4.1 Formal sources

Emotional support by health care professionals helped several participants to accept their HIV status.

“I was even able to accept the status. I was happy ...”

“... they were concerned ... it gave me hope and made me strong, gave me life ... they became like friends ...”

“... the lady phoning you ...helps to get you through the stages when you feel down and you don't want to drink it ... ja, it helps sometimes because they ask me like other questions, are you using the condom, all those things, it's like keep you reminded, say you must follow this things, it's so important in you life ... I just feel that they are concerned ... I take them as the people who knows and are helping me in some other ways ...”

These relationships sometimes develop unplanned and do not always consist of a formal structure. Some participants derive most of their support from a professional person that they have met during their treatment process.

“I've got my psychologist ...”

Rowe *et al.* (2005:266) found that the support provided by nurses to patients visiting their clinic, facilitate regular clinic visits and obtaining their medication on time. Almost all participants in this study mentioned the importance of healthcare worker support.

“... he phoned me at the work ...”

“... doctor helped you in an emotional way as well ...”

Most of the time participants made use of a combination of support from their health care providers and people from their social circle.

3.7.10.4.2 Informal sources

Having a partner is a main source of emotional support to most participants.

“... he do everything for me ...”

“... he’s supportive ...”

“I told him, I said, you know what, the doctor said I am HIV positive. He said ‘oh, no, don’t worry. That is not a problem’ ... which I suspect, he already know about his status ...”

“... everything I do, I do it with my husband. He was supporting form day one ...”

“... the support that I get is from my husband ...”

“... he never ran away ... he has been supporting me ...”

“I got the other boyfriend but he knows that I’m positive. I told him ... he’s been supportive to me. But I’ve also asked him to go for the test. So he must know that he is negative or that he is positive to so that living together and not knowing what is going on ...”

“He was the stronger one ... he has been positive he was the best thing that happened to me ...”

No participant indicated that having problems with her partner caused her to have difficulty with adherence.

“I don’t trust you ... I don’t trust you as a farther also, because ... you left your two kids with your mom, even though you saw that your kids was struggling ...”

“... you are going to look for another woman, immediately ... I discovered that he had a girlfriend ... it took me, the trust was gone ... I don’t trust him in the same way. The same way as before. Recently ... that actually said to me, oh, when I die, another woman is going to come and raise my kids. And what if that woman doesn’t want that kids ...”

“I feel I’m not sharing this with my husband, although he was supportive at the time. Although he was there, although he stayed. But all of a sudden I see him running away form it ...”

“if I die, he will be going round and tell everybody I gave the HIV to him. He will never admit that he gave it to me. That he’s previous girlfriends died of HIV ... he doesn’t want to carry the blame”

“If he’s not strong, what makes him feel he’ll be strong for me if I’m sick ... I’d rather die alone, knowing that I’m alone. I think that’s that. It’s that. Or dying then with someone who loves me ... then I would die peacefully ...”

“... why do you have t know about me, I’m you’re wife, and I shouldn’t know anything about you?”

“I’d rather be alone and happy than die in the arms of someone who doesn’t love me ...”

Most participants could identify at least one friend or family member who could provide them with emotional support.

“... my parents ... they are very much supportive ...”

“... my mother, definitely, although it will destroy her because she doesn't know at the moment ... I have a lot of people who actually love me and who make me feel wanted, except my husband ...”

“... she also doesn't want me to stay alone. Because she said I may start thinking about this ...”

“My mom was here, and luckily my mom is a nurse, so she would try to calm me and talk to me ... I was at home with my mom, so she was like making food for me and taking care of me before she goes to work ... she told my sisters and they are also very supportive ... but they were also scared ...”

“I have this friend, maybe someone I can call like I can call a dear friend, because I know every time ... and then my family, I, maybe my father ...”

“... my mom and my sisters and my boyfriend ... he also went for a check-up and he found out that he doesn't have it ... he didn't understand ... and so I told him that maybe it's not you, it might be my precious boyfriend. Because afterwards I learned my previous boyfriend died and I realised it might be that ...”

“I have very good friends ...”

“... my mother and my sister. Those are the ones actually who are giving my support. No, if I'm depressed, we are very close ... so if something were to happen, you know a drastic kind of thing, that started to make me bedridden, it would be a bit difficult for them to come and stay with me because they are far and they are working ...”

One participant mentioned that she deliberately befriended other HIV positive people.

“... and maybe I'm surrounding myself also with people that I know they are just like me ... I also have a friend ... she's also positive. But she's not yet on medication. And she looks very, very healthy. She wasn't ... she looks so healthy, more healthy than me ...”

Other support persons came from the society but were not closely related to the participants. They were mostly met after the participant had discovered her HIV status.

“... from the church, she also, she is a very elderly woman, she's about sixty. She's infected as well. So, I ask her a lot of questions. If I see something very strange on me, I'll give her a call and fortunately, she was, ja she was a matron, she's in the nursing ...”



"I'm quite grateful for that kind of support structure because other people don't have that ..."

"... you also have sufficient support in you social circle ..."

"... sometimes you think you're alone, a lot of people are suffering ..."

"I listened to radio ... I've got inspiration from the guy, from other people that I've seen ..."

Participants had different opinions regarding formalized systems for support, such as helplines and support groups. Some had previous exposure to one or more of these organizations and had different opinions on the value thereof.

With regard to utilizing support groups by people living with HIV, they found that the participants valued the existence of such facilities as it provided them with a sense of belonging, a place where they can disclose in safety, a source of social support and acceptance, as well as education. All of these factors played a role in adherence according to the participants (Rower, 2005:265-266).

"... help-line ... ja, I can use it as long as it's for the relevant answers ... no I would read it, I would say, no it's informative ... they check our internet ... I'd rather not ... if you send me the information, it's there, just go and read it. I will go and read it. Because it's related to my work ..."

Regarding support groups you feel you have handled all the issues surrounding your diagnosis, and you don't want to go back there ... you would rather move on.

While some considered using one of these systems, others did not feel the same way. One participant explained that she previously called a helpline only to find that they were unsupportive. She was therefore reluctant to use that facility again. Another participant, however, used the services and reported that at the time it had been easier to talk to a stranger.

"... and they are not positive ... the person I was talking to ..."

"... when I pick up a phone, like that day when I said I couldn't take it anymore, I spoke to a lady from the AIDS help-line ..."

"... it really helped to talk to somebody, and especially now it's nice to talk to a stranger ..."

“... counseling and support groups, help lines ... they are OK, but I have not yet been exposed to them ...”

None of the participants joined a HIV support group before. Different explanations were voiced.

“... you will not attend a support group as it brings out questions about trust ...”

“... one on one is better than a support group ...”

“... where there is an one to one conversation ... with some other persons you may feel shy to ask in a group. Sometimes you think, should I ask this question, maybe people would think I'm asking such a stupid question ... face to face it would be much better, because it's like you have that trust. Or sometimes like when you don't see that person, you might think he is just answering you just to ...”

“... a buddy system at the onset of treatment can work. But special attention must be applied to issues of confidentiality and trust ... they should both be comfortable with what is agreed ...”

“... share with the group ... but not now ...”

Several participants were, however, involved in non-HIV related support groups, mainly provided by their respective religious groups.

“... it's a support group ... they try to make your mind positive. They're telling you that it's through the grace of God that you must stay positive and you must fight the illnesses ...”

“I go to church, but truly speaking, I didn't tell them about my problem with the AIDS ...”

“... the support group there as well. So I do participate, but obviously without, you know, standing in front of the group and tell them this is what I am. And strange enough they started my friends to come to me and confess that they are like this. And I make sure that I, give them counseling ...”

Only one participant indicated that she would like to join a support group of HIV positive women, but did not know how to go about it.

“I'd like to join a group of women who are infected with the virus ... we give each other moral support, share our experiences ... sometimes people are so sick, they've closed themselves in this corner ... we all get strength from each other ... you see, it gives people hope ...”

Several participants indicated that they lost their primary support person after their diagnosis with HIV. To some, the loss of the support person was related to their diagnosis, while for others it was contributed to other factors. None, however, indicated that these incidents had a negative impact on their adherence.

“... we’ve been married for 5 years ... we’ve gone out for three years before we had this Lobola business going on. Then we got married ... he moved ...”

“I was in a long term relationship for at the time four and a half years ...”

“I broke up with him, two years after, so breaking up don’t have anything to do with the fact that this is what happened. It’s just that there were some issues, and fundamental issues that we couldn’t agree on ...”

“I was the one who broke off our relationship at the time. It wasn’t fair because maybe he will stay with me out of sheer obligation. And I can’t keep him with me against his will, because I’m sick. So I said I don’t want to see him anymore. And I knew the reason why I did this was to protect him to make him free so that he can go in case he is not sick, I’m the one who is ...”

“... in 2000 he left ... so I don’t know what’s happening and where ever he is ...”

“... we were together for about seven years ...”

“... my boyfriend passed away last year ...”

Although many participants felt that their partner at the time of their diagnosis was the infector, only one indicated that she could not continue a relationship with him.

“... even if I chase him out, he would have, he should have stayed ...”

“... he is putting me through hell because he doesn’t want to pay, for anything ...”

“I felt if I could just kill him ...”

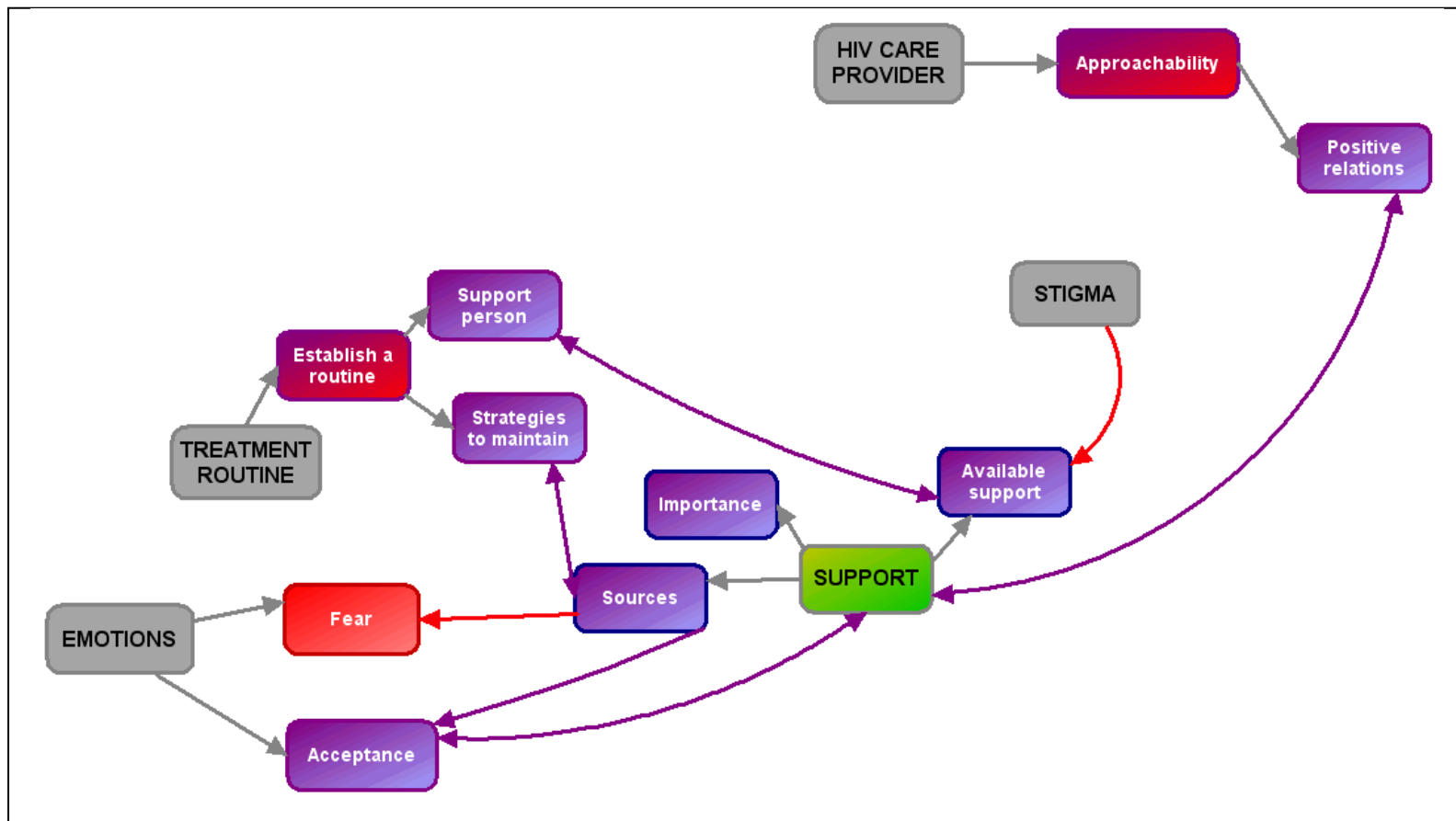


Figure 3.10.2 Aspects of support that influenced or might influence adherence in context

3.8 CONCLUSION

In this chapter, the research data was discussed according to the following themes:

1. Culture and religion
2. Emotions regarding HIV and its treatment
3. Cost of antiretroviral therapy
4. Side effects of antiretroviral therapy
5. Treatment routine
6. HIV care provider
7. Knowledge regarding HIV and antiretroviral therapy regime
8. Trust antiretroviral therapy to make a difference
9. The influence of stigma
10. Support

In Chapter 4 these themes and their categories and subcategories will be discussed at hand of the research question, namely

1. **Factors that inhibit or might inhibit adherence to antiretroviral therapy**
2. **Factors that enhance or might enhance adherence to antiretroviral therapy**



CHAPTER 4

CONCLUSIONS, RECOMMENDATIONS AND SUGGESTIONS FOR FURTHER STUDY

4.1 INTRODUCTION

Different factors that influenced or might influence adherence to antiretroviral therapy were identified by the participant in this study. These findings were described in chapter 3. No single factor could be identified that would under all circumstances influence adherence in a specific manner. Most factors were interrelated and some even displayed a difference in impact, depending on the circumstances and other mediating or aggravating factors.

One specific participant displayed a high level of knowledge regarding HIV and its treatment, and as expected according to the literature, also displayed adequate adherence. However, another participant indicated that at the onset of her antiretroviral therapy, she knew very little about HIV and that treatment was a totally foreign concept to her. Contrary to the literature, she too displayed adequate adherence.

4.2 FACTORS THAT ENHANCED OR MIGHT ENHANCE ADHERENCE

4.2.1 Children and adherence

In this study, caretaking responsibilities were identified as a positive influence on adherence. Participants indicated that they wanted to raise their children, gave them emotional support and help them to become independent adults. To achieve this goal,

these participants indicated that by taking antiretroviral therapy they will live longer. Their motivation for taking the antiretroviral therapy is therefore underscored by the belief that the medication will enhance their health and prolong their lives. At least two participants indicated that they wanted to make financial provision for their children. Children also played an important role in helping their parents to remember to take their medications.

Caretaking responsibilities that influenced these participants' adherence were both emotional and practical / logistical in nature

4.2.2 Support

Social support played a less important role than anticipated in this study. Although some of the participants went through socially and emotionally traumatizing events for instance separation, divorce and loss of a partner, none indicated that it had influenced their adherence adversely. However, almost everyone indicated that it is important to identify someone you can talk to about HIV related emotions and problems. Furthermore, the presence of social support, in particular by a significant other (partner), made adherence easier. It is difficult to determine whether the presence of perceived social support actually enhanced adherence. Feelings of acceptance might have enhanced acceptance of HIV as a disease, and of antiretroviral therapy, with consequent facilitation of adherence.

Partners and parents, except for children as discussed earlier, were the two groups identified the most by participants to help with the practical side of adherence. Verbally reminding participants of their medication times was the method usually employed.



4.2.3 Religion

None of the religious beliefs represented by the participants in this study interfered with adherence to antiretroviral therapy. However, religion played an important role in the level of acceptance to their disease and its treatment. It furthermore helped them to live life as normally as possible while cultivating hope. All of these factors may play a role in preventing or diminishing depression, a factor known to adversely influence adherence.

4.2.4 Acceptance of HIV and its treatment

Acceptance of the disease and the need to go onto treatment for the rest of their lives were emphasized as very important factors to attain adherence. Without acceptance, it might have been difficult to adhere to treatment due to feelings of loss of control over one's life and being trapped. Consequently these feelings might have led to a loss of hope and depression, which ultimately will interfere with adherence.

4.2.5 Believing in the potential benefit of antiretroviral therapy

To a varying degree, most participants believed that antiretroviral therapy would make a difference in their health and life expectancy. Some were so convinced that the treatment would be effective that they were somewhat oblivious to the dangers of resistance and the possibility of treatment being ineffective. Others, however, still harbor a deep rooted fear of dying and developing AIDS, and were thus extremely sensitive towards any strange symptoms, new developments on the market and media releases regarding the medication.

4.2.6 Treatment routine

In essence, all participants perceived a treatment routine to be important. To some it was a haphazard affair, developing over time through trial and error. However, to others it was a serious matter, prompting them to sit down and think it through. This process took one specific participant several months before she commenced with treatment.

Current daily routine and guidelines provided by the health care provider were used to determine a suitable treatment routine. In cases where the guidelines provided by the health care provider were not clearly understood or remembered, or the importance of these guidelines were not clear, participants tended to fit their treatment routine into their daily routine where they thought it would suit them best. It thus happened that the treatment routine was incorrect, causing non-intentional inadequate adherence.

4.2.7 HIV care provider

Participants preferred an HIV care provider who is approachable, non-judgmental and providing emotional and informational support. These services should be continuously available, especially in times of crisis.

Confidentiality and health care provider competence were two of the main pre-requisites mentioned by participants. Most, however, did not have a way to validate these requirements and built their health care provider relationships mostly on trust.

4.2.8 HIV literacy

Incidents of inadequate adherence by participants were often attributed to misunderstandings or lack of information. Some participants did not understand their dosing instructions correctly and took their medication incorrectly. Others

encountered problems related to the practicality of taking their medication and could not find a suitable way to counter the problem. They were thus knowingly inadequately adherent because they did not know of a better method.

4.3 FACTORS THAT INHIBITED OR MIGHT INHIBIT ADHERENCE

4.3.1 Tradition and culture

Depending on the degree to which it is enforced the traditional role of women may adversely affect adherence. According to most African customs, the woman is subordinate to her husband or even her partner. If she does not generate an income herself, or her income proves to be insufficient to support antiretroviral therapy, she becomes financially dependent. If for some reason he does not approve of her taking antiretroviral therapy, it may be due to competition of family needs or a lack of information that consequently encourages him to believe that the medication is harmful, she may then not be able to adhere to treatment. Even if she was able to obtain the medication from a government institution, she still would need money to regularly visit this facility for medication refills, follow-up at the doctor and blood tests. She would also need to hide her treatment from her partner/husband in case he sanctions her for taking the medication without his knowledge.

4.3.2 Stigma

Stigma regarding HIV and its treatment caused none of the participants to alter their level of adherence. However, many discussed circumstances in which stigma would influence adherence. The stigma enveloping antiretroviral therapy and especially the antiretroviral drugs, may cause hesitance in some people to commence treatment.

This fear and suspicion may ultimately interfere with adherence in situations where patients do not readily have access to accurate information, but are also in continuous contact with public speculation regarding antiretroviral therapy. Patients who become aware through the public media of possible toxic effects of one of the antiretroviral drugs that they are using, may stop the drug 'temporarily'. This is especially problematic if they do not have immediate access to a reliable source of information to calm their concerns.

The stigma of disclosure might inhibit adherence when patients have to take medication at times during the day when they do not have access to privacy, or are being caught up in work. If this fear of disclosure also reverts back home, where some patients' family members are not even aware that they are HIV positive, adherence can become extremely difficult. It also takes away this person's source of emotional, functional and financial support.

4.3.3 Rebellion and fear

Fear towards the effects of the antiretroviral drugs, or fear of disclosure may both influence adherence adversely, as discussed under the previous heading of Stigma. Fear towards the disease and what the future holds, may prove a patient to be incapable of adherence.

Rebellion, and therefore possibly any negative emotion, has interfered with the adherence of one particular participant. It is therefore important to reach a point of acceptance before one will be able to mobilize enough emotional resources to overcome obstacles towards achieving adequate adherence.

4.3.4 Cost of antiretroviral therapy

The overall cost of antiretroviral therapy proves to be a problem for many participants. This includes a lack of adequate funding for obtaining antiretroviral drugs, undergoing regular laboratory tests, follow-up appointments at the doctor and affording transport to achieve the three aforementioned components of adherence.

Funding facilities such as medical aids, often make provision for the financial aspects of antiretroviral therapy as far as the medication, laboratory tests and doctor's appointments are concerned, but very few providers take into account a patient's need for funding to obtain these goals.

4.3.5 Side-effects

Side-effects, whether real or expected, may interfere with adherence. Most participants are prepared to tolerate side-effects, especially when they are warned and informed about it beforehand. However, a lack of information may scare a participant into stopping her medication. Participants who have experienced severe side-effects and who could not access information, discontinued their treatment temporarily.

Continuously uncomfortable side-effects also caused participants to adjust their medication dose in an effort to reduce the effects. When doing this without the knowledge or consent of the health care provider, she runs the risk of developing resistance due to decreased drug levels.

4.3.6 HIV care provider

The disrespectful treatment of participants by health care providers caused them to abandon health seeking behaviour temporarily. Should these participants were using

antiretroviral therapy at that time, it might have caused treatment interruption. However, it caused a reluctance to seek further medical care for HIV.

The inability of health care providers to help patients to overcome obstacles regarding adherence is problematic, as the provider is usually the first place a patient looks for help. If the health care provider does not attend to this problem, the patient may interpret the consequent inadequate adherence as of less importance.

When a health care provider is not accessible when patients experience difficulty with antiretroviral therapy, they are often left to the mercy of substitute providers. All of the substitutes are not necessarily experienced in antiretroviral therapy and may thus provide a lesser service. Patients may also feel reluctant to disclose their HVI status to person unknown to them, and may prefer to wait until their health care provider becomes available again. This can have serious health consequences.

4.4 LIMITATIONS OF THE STUDY

Adherence literature in general could to date, not present a perfect solution as to which patients will, and which will not adhere to antiretroviral therapy. Factors that are known to impact on adherence have different levels of impact on individual adherence, ranging from none to severe. There are numerous interrelated, aggravating and mediating factors that are difficult to evaluate.

The population in this study is limited, and different factors may be identified in other populations. However, as no specific factor could be identified that applied to all participants in this study, it again emphasized the notion in literature to individualize interventions. Each patient should be assessed individually and all adherence interventions planned accordingly.

4.5 RECOMMENDATIONS FOR FURTHER STUDY

All the religious denominations of South Africa were not represented in this study. In order to truly determine whether religion could interact with adherence, a more extensive study, including all possible denominations, should be conducted.

The study was limited to black women attending an urban private healthcare facility for antiretroviral therapy. Should the study be repeated in other settings, some interesting information regarding adherence in different populations and sub-populations may come to light. For instance:

- ***Adherence experiences may differ amongst patients who receive their antiretroviral therapy in the private sector from those who access therapy in the public sector***
- ***Adherence experiences may differ between men and women, between different racial groups, between urban and rural populations and even between different age groups.***

In order to determine the real value and interrelations of individual factors, extensive further study is needed.

4.6 SUMMARY

Although adherence is known to be a cornerstone of antiretroviral therapy, it is unfortunately also challenging. Chapter 1 consists of a literature overview of adherence according to the following aspects:

1. The importance of adherence to antiretroviral therapy, with specific reference to virus resistance towards antiretroviral drugs
2. Influencing factors of adherence as identified and published by different researchers

3. The various methods currently used to determine adherence, with reference to their accuracy and practicality in clinical care

This study made use of a qualitative descriptive and exploratory research approach. This approach was selected as a better understanding of the factors that influence or may influence adherence in the South African context. Chapter 2 consists of a discussion of the following:

1. The research design
2. The research process with specific reference to the research population, sampling process and sample characteristics
3. The data collection strategies, with specific reference to the data collections settings, process, guidelines and methods and procedures
4. The process of data analysis
5. Measures to ensure validity and reliability
6. Ethical considerations
7. Limitations of the study

Chapter 3 consists of a representation and discussion of analyzed data AT the hand of existing literature. The data was organized under 10 themes, each consisting of different categories and sub-categories (*See Figure 3*). Data was also scrutinized for patterns, aggravating and mediating factors. These patterns and factors were discussed and graphically displayed under each theme.

In chapter 4, a summary of the factors that influenced or may influence adherence as identified by this study, was discussed at the hand of:

1. Factors that inhibit or might inhibit adherence to antiretroviral therapy
2. Factors that enhance or might enhance adherence to antiretroviral therapy

Limitations of the study and suggestions for further study were consequently discussed.



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APPENDIXES

Appendix A: Public health care facilities for antiretroviral therapy

(South African National Department of Health, 2004)

Province	District	Treatment Site	Number of Patients on Antiretroviral Therapy end of December 2004
Eastern Cape (11)	Nelson Mandela	Uitenhage Hospital	3 739
	Metro	Dora Nginza Hospital	
	Amatole	Frere Hospital Cecilia Makiwane Hospital	
	OR Tambo	Umtata General Hospital St Elizabeth Hospital St Lucy's Hospital	
	Alfred Nzo	Rietvlei Hospital	
	Ukhahlamba	Umlamli-Empilisweni Hospital	
	Chris Hani	Frontier Hospital	
	Cacadu	Settlers Hospital	
Free State (5)	Motheo	National Hospital	1 115
	Lejweleputswa	Bongani Hospital	
	Thabo Mofutsanyana	Mofumahadi Manapo Mopeli Hospital	
	Xhariep	Itumeleng CHC	
	Northern Free State	Metsimaholo Hospital	
Gauteng (23)	Johannesburg Metro	Helen Joseph Hospital Coronation Hospital Discoverer CHC Johannesburg Hospital Hillbrow CHC Chris Hani-Baragwanath Hospital Zola CHC Lillian Ngoyi Clinic	9 691
	West Rand	Leratong Hospital Carletonville Hospital Khutsong Main Clinic CHC	
	Ekurhuleni	Natalspruit Hospital Thembisa Hospital Far East Rand Hospital Daveyton Main Clinic CHC	
	Sedibeng	Kopanong Hospital Sebokeng Empillisweni CHC	
	Tshwane / Metsweding	Pretoria Academic Hospital Kalafong Hospital Laudium CHC Dr George Mukhari Hospital Shosanguve III CHC	



KwaZulu-Natal (32)	eThekweni	King Edward VIII Hospital RK Khan Hospital Prince Mshiyeni Hospital Addington Hospital Mahatma Gandhi Hospital	6 086
	Umgungundlovu	Greys Hospital Northdale Hospital Edendale Hospital	
	Amajuba	Madadeni Hospital Newcastle Hospital	
	Umzinyathi	Church of Scotland Hospital CJ Memorial Hospital Dundee Hospital	
	Ilembe	Stanger Hospital	
	Uthungulu	Ngwelezane Hospital Lower Umfolozi Memorial Hospital	
	Umkhanyakude	Mseleni Hospital Hlabisa Hospital Bethesda Hospital Manguzi Hospital Mosvold Hospital	
	Uthekela	Ladysmith Hospital Estcourt Hospital	
	Zululand	Benedictine Hospital Nkonjeni Hospital Vryheid Hospital	
	Ugu	Murchinson Hospital CJ Crookes Hospital Port Shepsone Hospital	
	Sisonke	Christ the King Hospital St Apollonaris Hospital Kokstad Hospital	
	Limpopo (7)	Capricorn	
Vhembe		Tshilidzini Hospital Siloam Hospital	
Mopani		Letaba Hospital	
Bohlabela		Mapulaneng Hospital	
Sekhukhune		St Ritas Hospital	
Waterberg		Mokopane Hospital	
Mapumalanga (12)	Gert Sibande	Evander Hospital Embhuleni Hospital Piet Retief Hospital Bethal Hospital	936
	Ehlanzeni	Rob Ferreira Hospital Tonga Hospital Shongwe Hospital Themba Hospital	
	Nkangala	Philadelphia Hospital	



		KwaMhlanga Hospital Mmamethlake Hospital Witbank Hospital	
Northern Cape (5)	Frances Baard	Kimberley Hospital	515
	Kgalagadi	Kuruman Hospital	
	Namaqua	Springbok Hospital	
	Karoo	De Aar CHC	
	Siyanda	Gordonia Hospital	
North West (4)	Southern	Klerksdorp / Tshepong Hospital	2 625
	Central	Mafikeng / Bophelong Hospital	
	Bojanala	Rustenburg Hospital	
	Bophirima	Taung Hospital	
Western Cape (30)	Metro	Khayelitha Site B	6 660
		Michael Mapongwana Clinic	
		Nolungile Clinic	
		Gugulethu Clinic	
		Tygerberg Hospital	
		Groote Schuur Hospital	
Red Cross Memorial Children's Hospital			
GF Jooste Hospital			
Langa Washington Road Clinic			
Hout Bay Main Road Clinic			
Masiphumelelo Clinic			
Westfleur Hospital			
Victoria Hospital			
Hottentots Holland Hospital			
Mitchells Plain CHC			
Tableview Clinic			
Eerste River Hospital			
Robbie Nurrock			
Central Karoo	Beaufort West Hospital	Mosselbaai Hospital	
		Knysna Hospital	
West Coast	Vredenburg Hospital	Cloetesville DH	
		Swartland Clinic	
		Malmesbury	
		Paarl (TC Newman) Hospital	
Garden Route	George Hospital		
Boland / Overberg	Hermanus Hospital	Worcester (Eben Donges) Hospital	
		Roberston Clinic	
Number of patients on antiretroviral therapy in South Africa at the end of December 2004			32 302



Appendix B: The Health Belief Model

Concepts	Definition	Application
Perceived susceptibility	One's opinion of chances of getting a condition	Define populations(s) at risk, risk levels; personalize risk based on a person's features or behaviour; heighten perceived susceptibility if too low
Perceived severity	One's opinion of how serious a condition and its sequelae are	Specify consequences of the risk and the condition
Perceived benefits	One's opinion of the efficacy of the advised action to reduce risk or seriousness or impact	Define action to take; how, where, when; clarify the positive effects to be expected
Perceived barriers	One's opinion of the tangible and psychological costs of the advised action	Identify and reduce barriers through reassurance, incentives, assistance
Cues to action	Strategies to activate 'readiness'	Provide how-to information, promote awareness, reminders
Self-efficacy	Confidence in one's ability to take action	Provide training, guidance in performing action



Appendix C: Self-Reported Questionnaire Assessing Adherence (Adapted)

Participant _____

Date _____

Please complete the questionnaire. All information will be handled in strict confidence. Information will not be linked to your name.

DIRECTIVES FOR ANSWERING THE QUESTIONNAIRE

Like most people, it is likely that you have missed one or several pills at some point in time. In fact, even the most disciplined people may not always take all of their medication as they should. The most difficult thing will no doubt be for you to remember the times that you have missed taking one or several pills. It is thus important for you to make an effort to remember so that your answers are as precise as possible. Take the time you need to answer.

Answer the questionnaire with only your **ANTIRETROVIRAL** medication in mind. The word “pill” is used to mean tablets, caplets or capsules. The expression “**miss one or several pills**” means **NOT taking** all your antiretroviral pills at a certain time. Answer **all** the questions by entering a number or by checking one of the suggested answers (Godin *et al*, 2003:331 Appendix).

















Question 1

How many antiretroviral pills have you missed during the last four days? If you haven't missed any write '0'.

	Number of antiretroviral pills you have missed			
	First dose	Second dose	Third dose	Fourth dose
Example	1	0	0	
Yesterday				
Day before yesterday				

Question 2

Select from the pictures the pills you take. Write the corresponding letter in the box marked ‘**Type of Pill**’. In the box marked ‘**Amount**’ indicate how many pills you take at a time. Also indicate if you take your pills with or without food in the box marked ‘**Food**’.

A  3TC	E  Crixivan	I  Kaletra	M  Viramune
B  AZT	F  Fortovase	J  Norvir	N  Zerit 30
C  Abacavir	G  Hivid	K  Stocrin	O  Videx
D  Combivir	H  Invirase	L  Viracept	P  Zerit 40



Question 3

During the previous 7 days, did you ...

	Yes	No		Yes	No
Go out for a leisure activity? (movie, show, physical activity etc)			Go to a restaurant?		
Go to a bar?			Go to a party?		
Sleep away from home?			Attend a meeting?		
Visit friend(s) or family member(s)?			Receive a visit from friend(s) or family member(s)		

Question 4

During the past 7 days, did one of the situations listed in question 3 prevent you from taking all your antiretroviral pills? Please describe.

Question 5a

During the last 7 days, how many times, in total, did you miss taking one or more of your antiretroviral pills? (If you haven't missed any, write down the number '0')

_____ **TIMES**

↳ **Question 5b** In total, this represents how many antiretroviral pills?
 _____ **PILLS**



Appendix D: The MOS Social Support Survey

Social support survey as amended by Rand Health

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/informational support					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Some whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problem	1	2	3	4	5
Tangible support					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support					
Someone who show you loves and affection	1	2	3	4	5
Someone to love you and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5
Positive social interaction					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5

How to score the survey

The survey consists of four separate social support subscales and an overall functional social support index. A higher score for an individual scale or for the overall support index indicates more support.

- To obtain a score for each subscale, calculate the average of the scores for each item in the subscale.
- To obtain an overall support index, calculate the average of (1) the scores for all 18 items included in the four subscales, and (2) the score for the one additional item
- To compare to published means in the article referenced below, scale scores can be transformed to a 0 – 100 scale using the following formula:

$$100 \times \frac{(\text{observed score} - \text{minimum possible score})}{\text{maximum possible score} - \text{minimum possible score}}$$

Higher ratings reflect higher access to social support, better quality of life and fewer role limitations.



Appendix E: Demographic Information

Age	18-29 30-39 40-49 50-59 60-69 70+
Marital status	Unmarried, living alone, no sexual relationship Unmarried, living alone, sexual relationship Unmarried, living with someone, no sexual relationship Unmarried, living with someone, sexual relationship Married, no extramarital sexual relationship(s) Married, extramarital sexual relationship(s) Divorced/separated, living alone, no sexual relationship Divorced/ separated, living alone, sexual relationship
Racial Denomination	Nguni Zulu Xhosa Ndebele Swazi Sotho Tswana Tsonga Venda
Income per anum	No income R 1 - R 400 R 401 - R 800 R 801 - R 1600 R 1601 - R 3200 R 3201 - R 6400 R 6401 - R 12800 R 12801 - R 25600 R 25601 - R 51200 R 51201 - R 102400 R 102401 - R 204800 R 204801 or more
Job description	
Highest education level	< Matric Matric Tertiary education
Means of payment for medication and health care	Medical Aid 100% Medical Aid with co-payment Company Benefit 100% Company Benefit with co-payment Own Funding



Appendix F: Clinical Information

Where you previously on different antiretroviral drugs than the ones you are currently using.	Yes No			
If you answered yes, please name them				
CD4 history (File)	Date	Result		
Viral load history (File)	Date	Result		
AIDS Surveillance Case Definition for Adults and Adolescents (Researcher) (Bartlett & Gallant, 2003:3)		Clinical Categories		
		A	B	C
	CD4 cell categories	Asymptomatic, or PGL, or Acute HIV Infection	Symptomatic (not A or C)	AIDS Indicator Condition (1987)
	> 500/mm ² > 29%	A1	B1	C1
	200 – 499/mm ² 14 – 28%	A2	B2	C2
< 200/mm ² < 14%	A3	B3	C3	
Since when are you on treatment for HIV				
State all previous opportunistic infections				
What antiretroviral therapy are you currently using (from Adherence Questionnaire)				



Appendix G: Interviews

INTERVIEW I – Medical and Treatment Related History

- Did you have any previous experience with adherence to other medication, i.e. medication for infections
- Did you have any previous experience with ART?
- How did it go?
- How did it come that you started with ART? (Received prescription?, co-decided on treatment?, involvement)
- For how long will you be taking ART?
- How do you feel about the length of the treatment?
- What do you believe can this treatment do/mean to you?
- Identify events or factors that interfered with adherence, especially during the previous month?
- How did you overcome these obstacles?
- How can you overcome these obstacles?
- Would you like to tell me how you learned / discovered that you are HIV positive?
- How did it make you feel
- How did it happen that you start on treatment for HIV?
- If you think back to the time you started with the treatment, how did it go the first week?
- How did you manage to teach yourself to keep to your treatment prescription?
- Did you experience any side effects?
- Did you feel, back then, that you received enough information regarding treatment and HIV before you started?
- Who else know you are HIV positive
- Would you ever tell anybody else, besides the people who already know, that you are HIV positive?
- How did people react when you told them you are HIV positive
- Do you have children?
- How does children interfere with taking your medication on time without skipping any doses
- Is there any reason why you would rather not take medication
- What are the reasons why you prefer to take medication

INTERVIEW II – Knowledge Regarding HIV and Antiretroviral Therapy

Let us pretend you are asked to give information regarding anti-HIV medication to someone with HIV. The person gives you the following statements. Please give your comment on these statements:

- I can stop my anti-HIV medication when I don't feel ill anymore
- I am becoming sicker because I have to start taking antiretroviral drugs
- My friend is also HIV positive, but he/she takes different medication than I do. Am I taking the correct drugs?
- I can never again, for the rest of my life, stop taking anti-HIV medication
- If my doctor changes my medication it is no longer working properly against the HIV
- The HIV can learn how the anti-HIV medication looks like, and build a defense system around it.
- The HIV can continue growing even while I take anti-HIV medication
- The HIV medication control the HIV by



- I forgot to take my morning dose I will take it with my next dose to make up
- I went to the pharmacy to get medicine for flu. It is OK to take it with my anti-HIV medication as a prescription to obtain it was not needed
- The side effects from anti-HIV medication only last for 2 weeks
- As long as I feel healthy, I don't need regular check-ups and blood tests
- If I skip a dose of my anti-HIV medication I will fall ill tomorrow
- If I skip one dose a week, I am still OK, but if I skip 3 doses, I will become ill
- I am taking only one anti-HIV medication, therefore I am healthier than someone who needs to take 2 or 3 different anti-HIV medications
- The anti-HIV medication makes me vomit / gives me diarrhoea. I will just wait it out, it will have to stop sometime

INTERVIEW III – Health Care Services

In an ideal world, if you can let your imagination run free, what will the health care services provide to

- Help you with emotional issues regarding HIV
- Medical aid issues
- Ordering and dispensing medication
- Laboratory testing
- Doctor's visits
- Information regarding HIV and related issues

Regarding treatment, what are the important issues, and which issues are less important?

INTERVIEW IV

- How does courtship and marriage work in the cultures you know?
- How easy is it to get a divorce?
- How much say does a woman have in your culture?
 1. Regarding sexual intercourse
 2. Pregnancy
 3. Delivery
 4. Raising the kids
- What is your traditional role as a woman?
- Who are responsible for raising the kids?
- Who are responsible for caring for the sick?
- Who are responsible for the household?
- What do you think will happen to you one day when you die?
- What is your culture's perspective on HIV / AIDS
- What is your culture's perspective on traditional medicine?



- What is your culture's perspective on Antiretroviral therapy?
- What myths do exist in your culture regarding HIV / AIDS?

INTERVIEW V

Did you attend a session with a <i>health care worker or doctor</i> about your treatment <i>before you start your treatment</i> ? <i>Who was is?</i>	
Can you describe, when you started on treatment, <i>how you decided to drink your medication</i> as you are doing now?	
Would you consider a <i>preparation session</i> before starting on treatment as important?	
Medication & Side Effects	
Experiencing <i>side effects</i> influenced your adherence. How?	
Keeping an <i>extra dose</i> on hand can promote adherence.	
Keeping a <i>snack</i> on hand, when you need to eat something before taking your pills, can enhance adherence.	
Does special <i>storage requirements</i> like keeping your medication in the fridge, have an influence on your adherence?	
Regime	
How important is establishing a <i>routine</i> when sticking to your treatment schedule?	
Is it easier to take your medication in front of other people, if you <i>pretend</i> it to be something else, like vitamins or blood pressure medications?	
Can you <i>describe the circumstances you forgot to take, or took your medication late</i> ?	
Will it be more difficult to keep to your treatment schedule if you had to take <i>double the amount</i> of pills you are currently taking?	
Will it be more difficult to keep to your treatment schedule if you had to take your pills <i>more frequently</i> , like three or four times a day?	
Can having a <i>checklist</i> help you to adhere to your treatment schedule?	
<i>How did you manage to establish a routine</i> when you started on treatment?	
The length of <i>time you are on treatment</i> , does that influence adherence?	
Can <i>previous treatment interruption</i> influence your current adherence?	
When you are <i>sick</i> does that influence your adherence?	
When you feel <i>healthy</i> does that influence your adherence?	
When you become <i>healthy after being sick</i> and on treatment, does that influence your adherence?	
How do you ensure that you get your <i>next medication issue</i> before the current ones are done?	
Lifestyle	
What kind of <i>lifestyle changes</i> did you have to make to accommodate your treatment regime	



When you have friends or family <i>staying over</i> at your house, does that influence your adherence?	
Does working <i>irregular hours</i> , or working at <i>different locations</i> , influence adherence?	
Can <i>changes in your day-to-day living</i> , like holidays, disease, death in the family, influence your adherence	
Primary Health Care Provider	
Being able to phone your <i>doctor</i> for a <i>new prescription</i> can influence your adherence	
Being able to phone your <i>doctor</i> when experiencing <i>side effects or strange symptoms</i> , can influence your adherence	
Being able to phone your <i>doctor</i> for <i>information or emotional support</i> , can influence adherence?	
Can <i>sticking to one doctor</i> for all your health needs, influence your adherence?	
Does <i>explaining</i> your treatment <i>progress</i> influence your adherence?	
If you were to be provided with a <i>plan of action</i> for most likely emergencies, like when the doctor is going away etc, would that influence adherence?	
Do you think your doctor's <i>personality or attitude</i> can influence your adherence?	
If you have <i>difficulty adhering</i> to your treatment schedule, would you ask your doctor to <i>change your treatment</i> , or try and cope?	
Can the <i>accessibility</i> of a doctor for <i>consultations</i> , influence your adherence?	
Can the <i>personality and approachability</i> of the doctor influence your adherence?	
If the doctor in any way, display information regarding <i>HIV</i> in his <i>consulting rooms</i> , would that influence your adherence?	
Can <i>loosing</i> your primary <i>health care provider</i> influence your adherence?	
Do regular <i>check-ups and blood tests</i> influence your adherence?	
Emotional	
Do you experience <i>fear of not taking your medication the correct way</i> ?	
What do you think can be the <i>cause of this fear</i> ?	
Can you describe what you <i>felt and did</i> when you were told it's time to <i>commence treatment</i> ?	
Would you say that arriving at a point of self <i>acceptance</i> is important for good adherence?	
Can <i>negative feelings</i> or fear influence adherence?	
Do you sometimes <i>feel fed up</i> , as if you don't want to go on like this for the rest of your life?	
Can <i>fear</i> influence adherence?	
Support	
How do you think it will influence your adherence if you <i>partner did not know</i> you are taking <i>medication</i> ?	



Does it influence your adherence when <i>someone else</i> you are close with, are also on <i>treatment</i> (not necessarily for HIV, but other chronic diseases as well)?	
If your <i>partner understands HIV</i> and its treatment, will that influence your adherence? What would happen if he/she doesn't understand?	
Finding out your <i>partner might have been unfaithful</i> , did the feelings brought along by this realisation influence your adherence?	
How do you think can your <i>support system</i> influence the way you take your medication?	
Can a <i>buddy system, support group or help-line</i> influence adherence?	
Stigma	
<i>Not disclosing your HIV status</i> to family or friends, does that have an influence on your adherence?	
<i>Not disclosing your HIV status to another doctor</i> or health care professional, does that have an influence on your adherence?	
The <i>stigma</i> that labels a person can influence adherence.	
Health Related Knowledge	
Do you think it's important to <i>learn about HIV</i> and its treatment to be able to adhere to your treatment schedule? Would it make a difference in your initial adherence if you knew then what you know?	
Attitude towards HIV	
People need to take <i>responsibility</i> for their own health and treatment before they can successfully adhere.	
Can a <i>positive mindset</i> influence your adherence?	
Do you think your <i>personality</i> influence your adherence?	
Believing that the <i>treatment will help</i> you, can influence your adherence.	
Being <i>pro-active</i> (manage your disease) can promote adherence	
What would you consider as <i>reasons to live</i> ? Does that influence your adherence?	
Does your <i>general attitude towards your health</i> influence your adherence?	
Women and HIV	
<i>Culture, religion and education</i> can influence a person's adherence.	
<i>Education</i> can play a part in the extent to which a <i>woman</i> adheres.	
<i>Financial independence</i> can play a part in a woman's adherence.	
If women <i>don't have a say in their personal and social lives</i> , will that influence adherence?	
Can being <i>pregnant</i> influence your adherence?	
Can <i>social class and structure</i> influence adherence?	
Paramedical Providers	
If you have to <i>collect your medication</i> with a script in hand, from the <i>pharmacy</i> , could that influence your adherence?	



When you experience difficulties with your <i>medical aid</i> paying for your medication, blood tests or consultations, would that influence your adherence?	
Do you believe the medicine of the <i>traditional healers</i> can help you? How does that influence your adherence to the western antiretroviral drugs?	
Finance	
If you pay for your medication, blood tests or consultations from your <i>own pocket</i> , would that influence your adherence?	
Responsibilities	
Does having <i>children</i> influence your adherence?	
General	
Do you think it's best for adherence to <i>be reminded of your status</i> and being on treatment regularly, or not?	
Can <i>communication or language</i> influence a person's adherence?	

Appendix H: Interviews with personnel at the private health care facility

INTERVIEW WITH DOCTOR AT PRIVATE HEALTH CARE FACILITY

- 1. How are patients prepared for treatment?**

During a consultation the doctor would discuss antiretroviral therapy with a patient. The benefits and possible side effects are discussed. Adherence is specifically addressed, mainly in terms of how the medication should be taken, and the consequences of inadequate adherence.
- 2. Their views on the levels of adherence for patients visiting the facility**

Good as most of the long term patients are on antiretroviral therapy for five to seven years without need to change the treatment due to probable virus resistance.
- 3. What are the attitudes of patients regarding adherence?**

Most patients are very positive. They understand what it is all about. Most patients will volunteer information regarding inadequate adherence.
- 4. Possible reasons for inadequate adherence, as emerging from their own experience as well as from statements made by patients.**

Patients mainly have difficulty with adherence because of psychological stress. This can be personal or caused by external factors like death in the family.
- 5. Intervention and support provided by the facility to enhance adherence.**

Patients who seem to struggle accepting their diagnosis and the necessity of treatment, are referred to their counselor, a psychologist or a psychiatrist.
- 6. How was continuity of support ensured during holidays and leave of absence?**

The doctor is seldom away for more than two weeks. During that time the health care facility are still open with at least a receptionist on duty. Patients can thus still collect their medication when it's delivered at the facility. All HIV positives receive the doctor's cellular phone number in case of an emergency. He is almost always available on his cellular phone, or will return the call when a patient leaves a message.
- 7. What is the procedure followed when a patient is suspected of being inadequately adherent?**

Patients who persist in inadequate adherence will eventually have to stop treatment. This is however a very difficult decision and only seen as a last resort. Patients are firstly referred for psychological help as discussed in point 5.

INTERVIEW WITH PROFESSIONAL NURSE AT PRIVATE HEALTH CARE FACILITY

- 1. How are patients prepared for treatment?**

Preparation for treatment varied amongst patients. As soon as a patient needed to start treatment, aspects such as benefits and side effects, consequences of inadequate adherence and duration of treatment were discussed. Patients who were diagnosed HIV positive but needed not to start on treatment presently had more time to be prepared for treatment. During follow-up sessions information was again discussed and re-enforced. Unfortunately, some patients, especially those coming from other parts of the country or other countries, were usually



pressed for time, and very limited time was available for treatment preparation. Psychologically preparedness for therapy was one of the important factors stressed by her.

Patients were followed-up after one month on therapy. They were also asked to contact her during office hours when they experience side effects or had other difficulties regarding the treatment.

2. Their views on the levels of adherence for patients visiting the facility

Adherence was on average good. There were however exemptions, although they were few. Patients who commenced treatment were asked to bring their medication containers along when coming for their first few follow-up visits. Pill counts were then performed. As soon as they were perceived to be adequately adherent, adherence was judged according to viral load suppression.

3. What are the attitudes of patients regarding adherence?

Mostly good. Most patients were contacted regularly. Patients sometimes experienced difficulties, but even when experiencing side effects, they stayed positive. This might be contributed to the availability of either the doctor or the professional nurse for enquiries and that most patients attending the facility have relative easy access to antiretroviral drugs.

4. Possible reasons for inadequate adherence, as emerging from their own experience as well as from statements made by patients.

Patients mainly have difficulty with adherence because of difficulty obtaining medication. This was especially true for patients from other countries. Financial constraints and side effects also played a role. Some patients stopped their medication although they knew they should not until they discussed it with the doctor. About 10% of patients had difficulty understanding the concepts of treatment and the infection. Very few patients had trouble understanding English or Afrikaans. When this occurred, the filing clerk was asked to act as a translator.

5. Intervention and support provided by the facility to enhance adherence.

Patients in need of special support received the professional nurse's cellular phone number. She was also available during office hours for personal or telephonic consultations. The atmosphere in the facility also contributed. Patients were treated as friends and equals. Care was taken to develop a relationship with each patient. Patients commencing treatment were given the cellular phone number of the professional nurse for use in an emergency. They tend to contact her regularly at the beginning, but needed less and less support as time goes by.

6. How was continuity of support ensured during holidays and leave of absence?

Communication in general was good between personnel and patients. Notes were placed on patient files regarding specific interventions. When going on leave, a substitute professional nurse, familiar with the facility, were briefed on matters still in process. She would then also contact the professional nurse when necessary.

7. What is the procedure followed when a patient is suspected of being inadequately adherent?

An appointment was scheduled with the patient during which the implications of inadequate adherence are discussed again. The doctor was also briefed on the intervention and then conducted a similar discussion with the patient. Responsibility for own treatment was stressed. In extreme cases where patients refused to adhere in spite of numerous interventions, treatment was stopped. Patients were also referred for psychological help.

Appendix I: Immune status of each participant and the antiretroviral regimen the participant used at the time of data collection

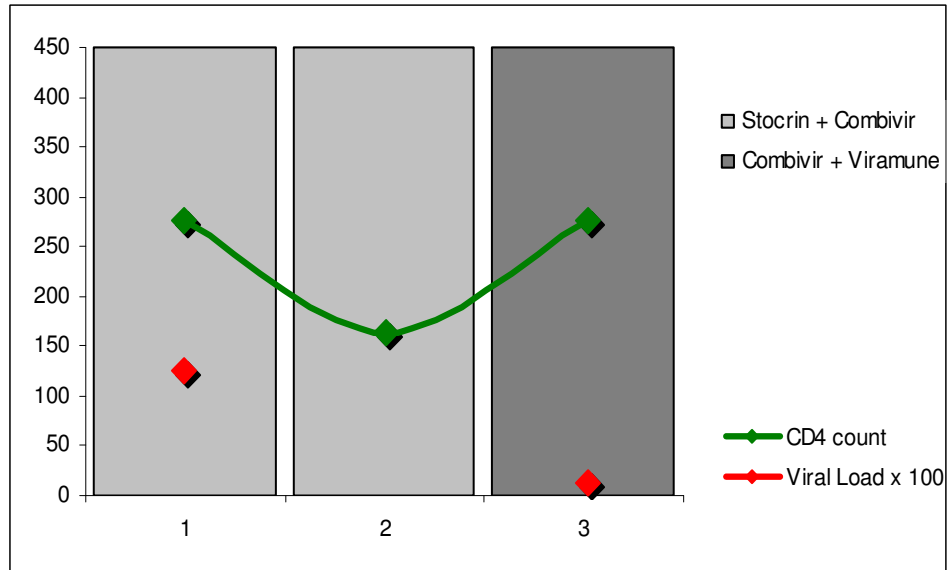


Figure 2.6 Immune status and antiretroviral treatment regimens of Participant 1

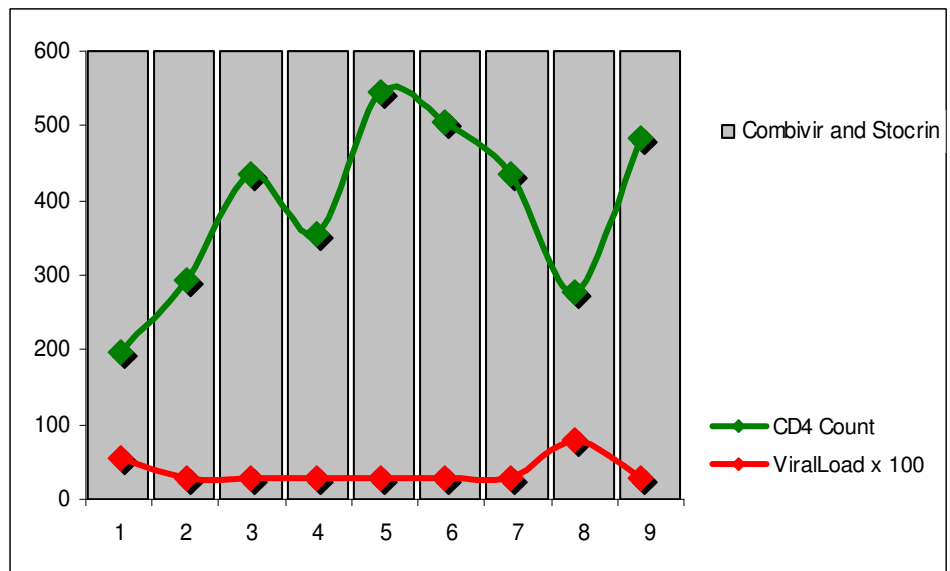


Figure 2.7 Immune status and antiretroviral treatment regimen of Participant 2

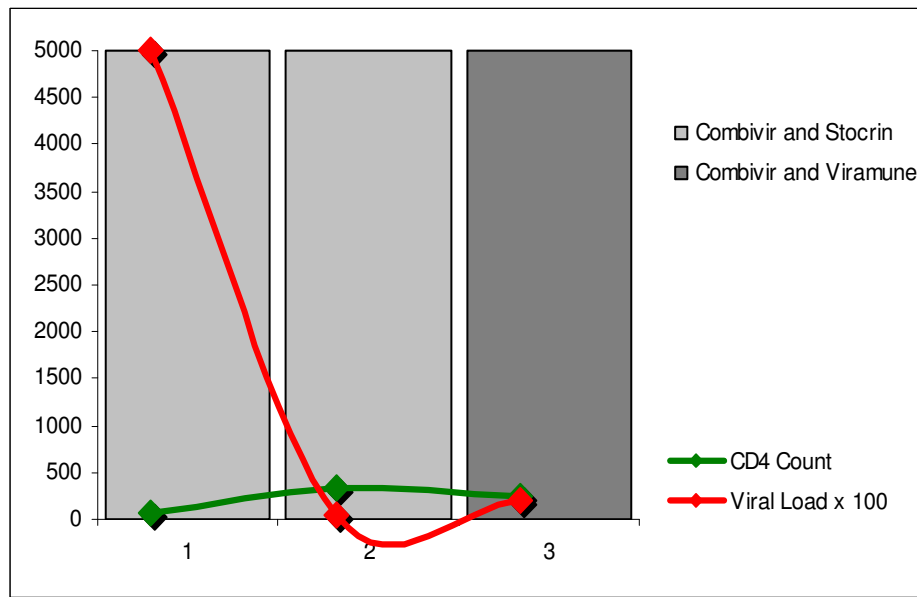


Figure 2.8 Immune status and antiretroviral treatment regimens of Participant 3

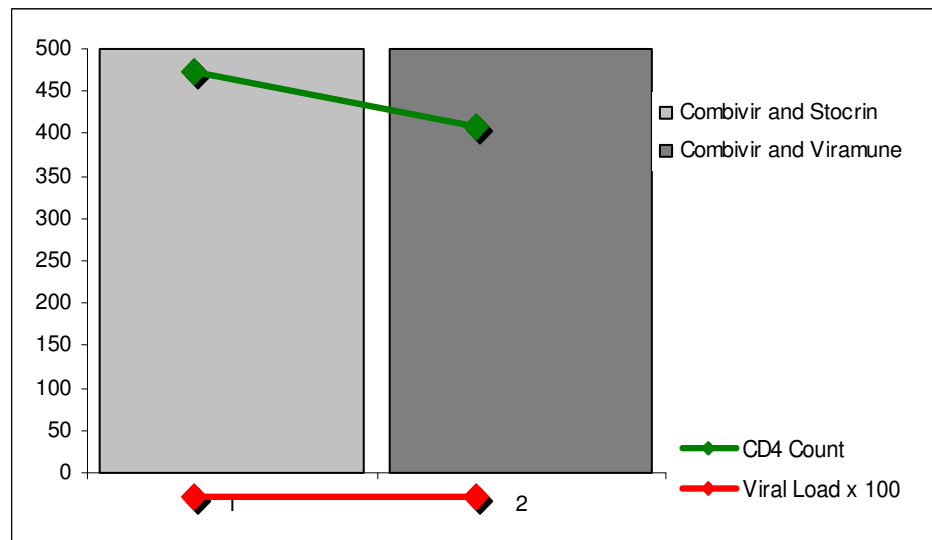


Figure 2.9 Immune status and antiretroviral treatment regimens of Participant 4

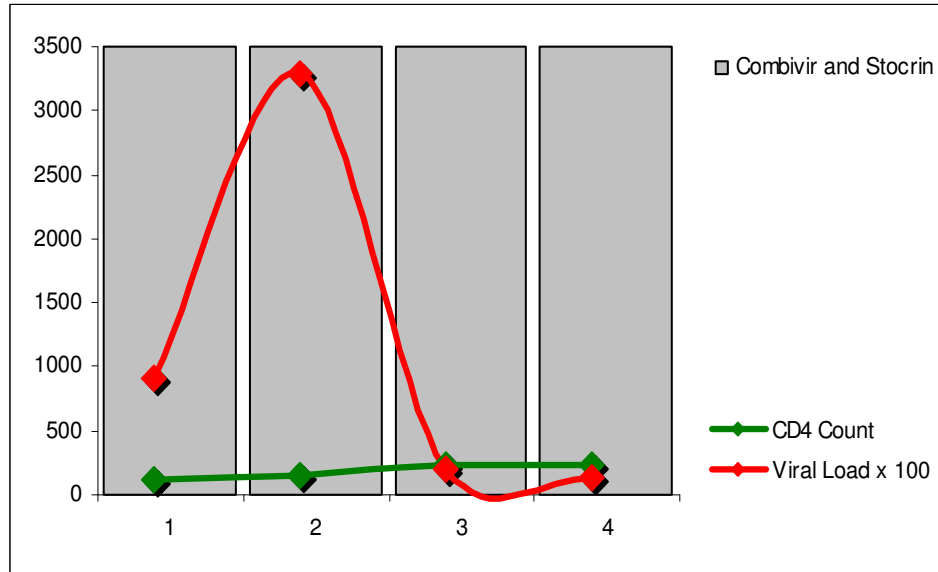


Figure 2.10 Immune Status and Simultaneous Antiretroviral Treatment Regimen of Participant 5

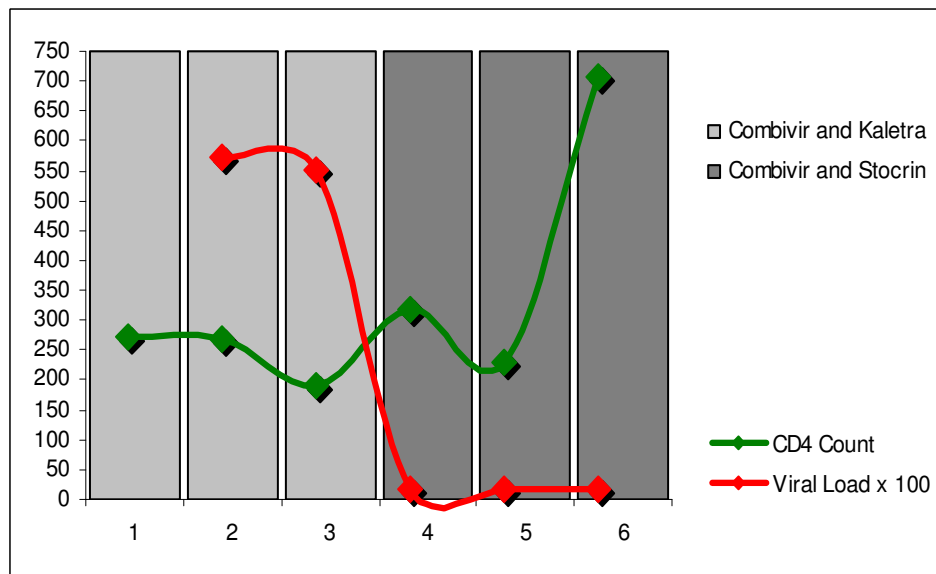


Figure 2.11 Immune Status and Simultaneous Antiretroviral Treatment Regimen of Participant 6

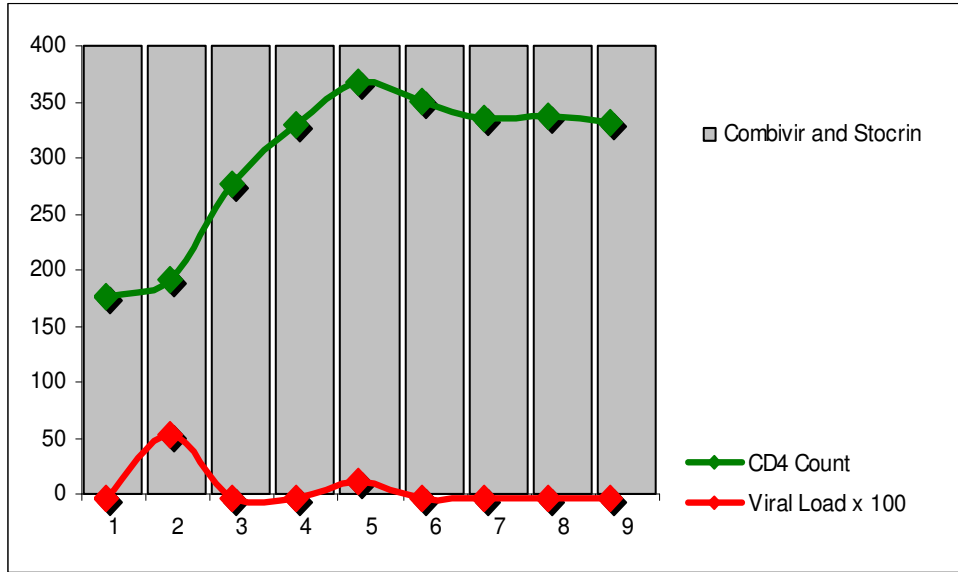


Figure 2.12 Immune Status and Simultaneous Antiretroviral Treatment Regimen of Participant 7

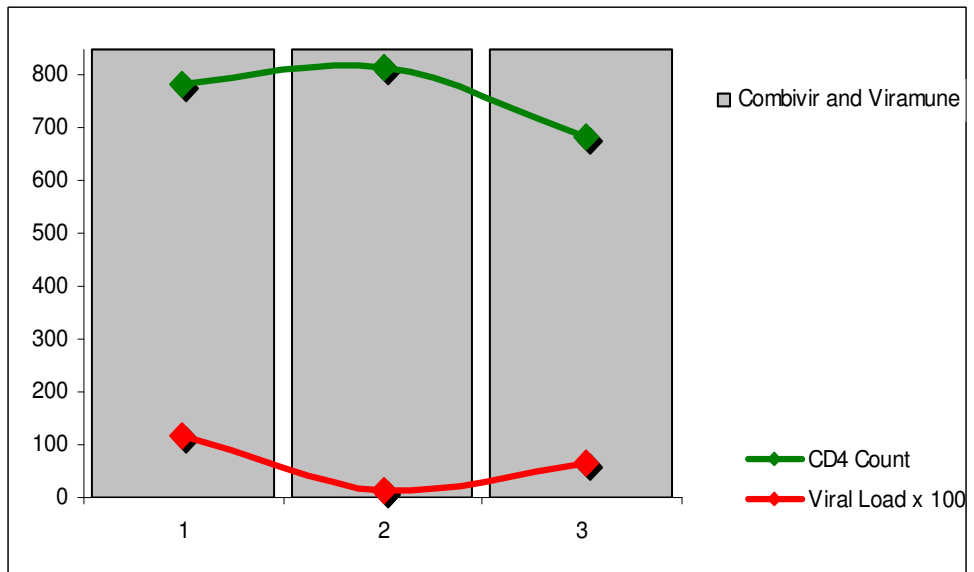


Figure 2.13 Immune Status and Simultaneous Antiretroviral Treatment Regimen of Participant 9

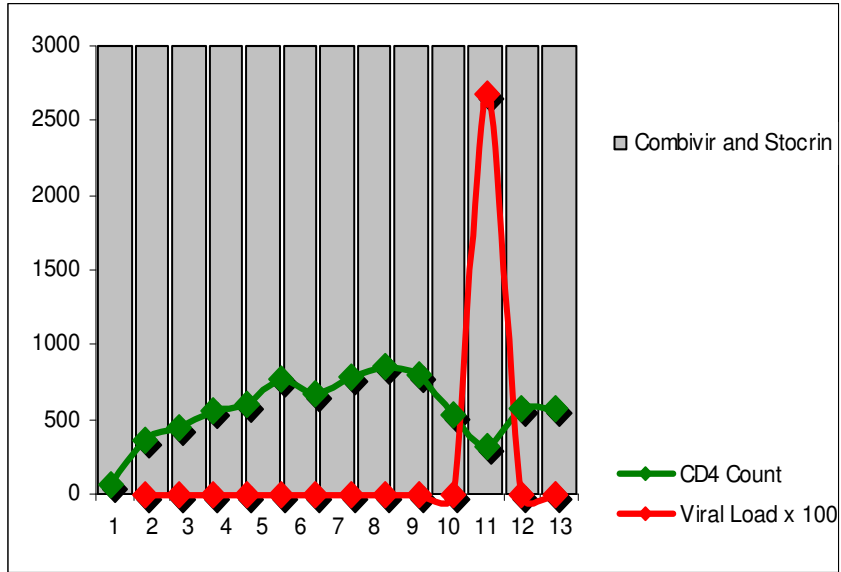


Figure 2.14 Immune Status and Simultaneous Antiretroviral Treatment Regimen of Participant 10

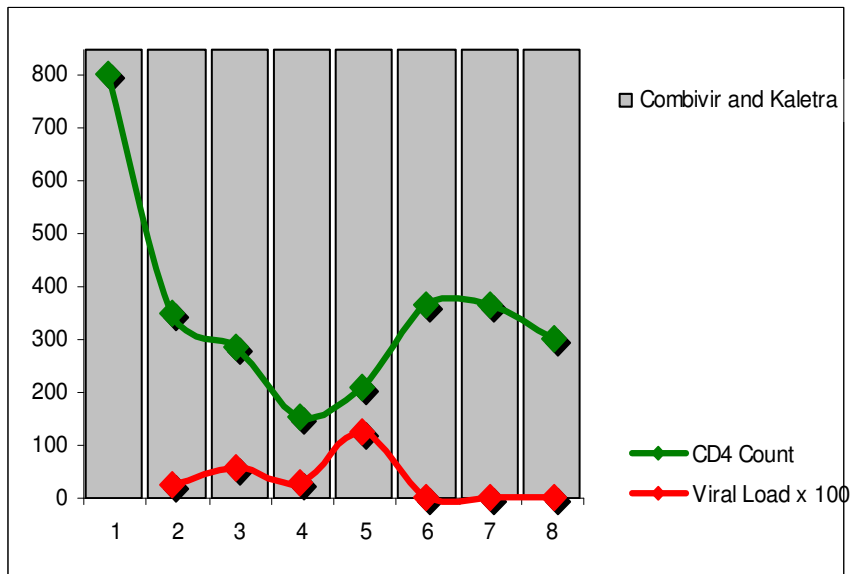


Figure 2.15 Immune Status and Simultaneous Antiretroviral Treatment Regimen of Participant 11

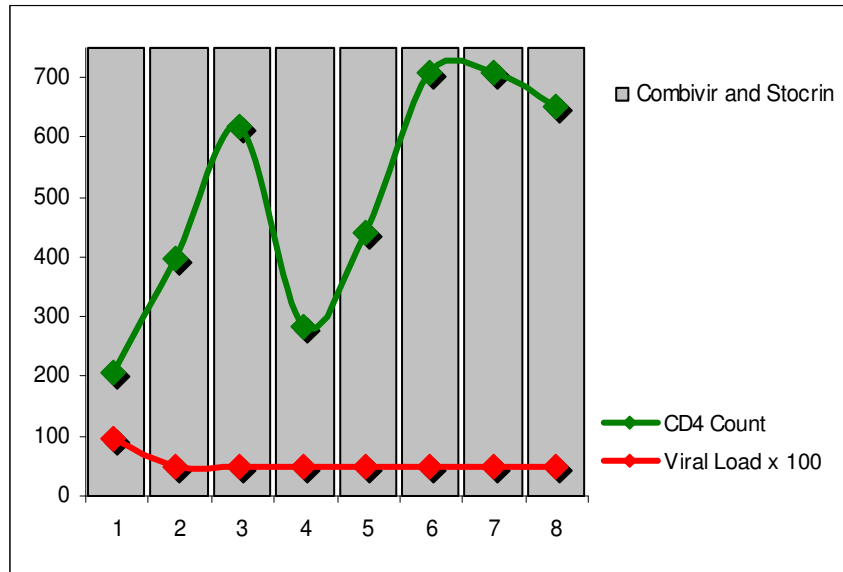


Figure 2.16 Immune Status and Simultaneous Antiretroviral Treatment Regimen of Participant 12



Appendix I: Example of transcribed interview

Are you fine?

Hm

Did you manage to work out the ...?

Ja, ja, I'm taking it now half past eleven ...

OK, and it works well?

Ja, it works well. I think for the past two weeks I started to set an alarm ... to notify my when it's half past. So now I'm used to it[7/3].

OK, so it took you a week to get used to the ...well good, I'm glad it wasn't that difficult. Hm, did you miss anything yesterday or the day before?

No

And you are still taking Stocrin and Combivir?

Yes

And now half past eleven ... ne? Half past ten ...?

How I'm drinking it now? It's half past eleven.

And did you do anything the previous week that made it difficult for you to take the medicine?

No

Anything from work or social

No

So you didn't miss anything the previous week.

The previous week ... it's not that I missed, but I was asleep and then I wake up late and take it[7/3]. So it's not like I ... it was like half past twelve, or there about

OK, but an hour ... but you took it anyway.

OK, anything specific that you want to talk about today?

No

Then I want you to tell me, in an ideal world, where you can have the perfect doctor and the perfect health system, and the perfect everything ... how would you like that to be to make it easier for you to be on therapy?

If it can be like the doctor can always contact you like maybe for ... not like every day, like maybe ... maybe if he can contact me once a month, or just to find out how am I doing ... am I OK, am I taking my medication. And just keep me informed if something happen in their field[7/3]. Maybe something in the HIV, maybe something came up and they can always inform their patients, you know, this thing is coming up ... maybe with the diet also. They tell us eat

healthy food and do exercise and all those things, they do. But sometimes they can even go further as to why it is that you are not supposed to do[7/3]. Just like to keep us informed.

More information and more special information ...

More information, ja

So that you grow into the thing, not everything in the first ... and then afterwards he's just issuing prescriptions.

Ja,

So it should be a more mutual relationship?

Something like that ...

If you have a doctor who phones you once a month and ask you ... like the medical aid lady, just want to know how you are ... would you be more willing ... prepared to phone that doctor when you have a question or a problem?

The only time that I'm phoning is when I'm feeling something[7/3]. When I'm suspecting something. I'm not OK, or maybe I have a rash ... what then.

OK

Ja, I would definitely phone the doctor and find out

But you do that now as well. When you have a problem ...

Ja, it's like when I'm feeling something, and when ...

And when you just have a question? You heard something on TV that is not in line with what you know, you want to confirm the information with someone, do you think there is someone that you can call?[7/3] *To tell you that ...*

Hm, no[7/3] ...

No

Would it be nice if you had access to an expert ... who can be there for you, clarifying questions ...?

Ja, hm-hm

There is a lot of information out there that is contradicting, that is confusing people.

Ja, there is especially with the medication. Sometimes some other people, you hear it on the TV, they got some side effects, but they don't go and tell you I have side effects, they just say this medication is not good. But if you ask yourself why are the doctors giving us these medication, then you find out it's this[7/3].

OK, now that we are at the problem of the medication, when you sat in the doctor's office the first time you received the prescription did you know about it then? There are these rumours and there are side effects and ...

No ...



Back then, no. And afterwards when you found out and you heard about these side effects, did you feel you can ask the doctor why does he prescribe you things that's bad for you?

No

Don't you feel comfortable talking to him like that?[7/3]

No, I don't[7/3]

You just trust him

OK, so if you have a real concern about the medication, would you ask him if it's fine to take it?

Hm, ja, from now onwards I think it's like I have to be concerned whatever is happening. I have to know exactly what is going on[7/3].

But in the beginning you wouldn't have asked questions.

Do you think it's because there is not that relationship between a doctor and a patient in the beginning?[7/3] You don't know him ...

Ja, something like and then you just think, OK, the doctor knows everything[7/3].

Isn't it scary if you hear that doctors sometimes make big boo-boos ?

Ja, sometimes you feel like, or maybe you feel like you have this thing ... you don't know much, the doctors know much. So whatever they say, you just go with it[7/3].

OK, would it helped if you had more information about the medication, back then? Maybe like in more informal. Not like you talking to the doctor, more like ... I know it's a problem with confidentiality, but say it was another disease like hypertension, and a few patients came together with someone who knows about the subject, and they discuss all the things they think about and worry about. And sort out everything until everybody is comfortable. Some sort of forum ...

Ja, hm, I think that would be much better, especially other things, what scares me is having a child. All those things, ja. And about breastfeeding. Most of the time it is like I get it from the magazines or from the radio that you don't have to breastfeed. All those things, what you must do, the medication, look after yourself if you are wanting or pregnant. All those things, I think, ja.

But you would want to know what is the exact risk, the deeper things.

Now how do you think can we go about having this type of forum? Where people can exchange ideas, think about things and discuss things without breaking confidentiality?

It would depend on the trust between the patient and that person, or else other patients who are not scared about their status[7/3]. They can have, maybe it's OK if they can have something like a forum, where they can exchange But I think the people who attend it would be the people who are open about their status. They don't care. But if you are like you want to keep your status confidential, it's somehow difficult, or maybe it can be through telephone, maybe a call conversation, maybe a toll-free or something[7/3].



Would it be OK if you go and see someone, for instance me, with an appointment, when you have a problem. We type of build a relationship ...

That's also, ja, something like that also can work. Where there is an one to one conversation ... with some other persons you may feel shy to ask in a group. Sometimes you think, should I ask this question, maybe people would think I'm asking such a stupid question[7/3].

OK, so a one to one would be better, telephonically or face to face.

Sometimes, it may depend, face to face it would be much better, because it's like you have that trust. Or sometimes like when you don't see that person, you might think he is just answering you just to[7/3] ...

Not giving attention ...

Ja, ja

But some issues might be OK to answer over the phone, If you want to know all the how and why of it, you make an appointment.

OK, doctors' visiting hours, is that a problem to you? Or do you think it can be a problem? It it's only from 10 or 11 in the morning until 5 in the afternoon, and not over weekends.

The problem is that I'm working, and the transport[7/3].

And you have to come and see him how much a year? 3 or 4 times?

3 or 4 times. Every time I have to ask them and then they drop me here[7/3].

Did you ever feel that asking that much time of from work is compromising your confidentiality? Oh she's taking off so many times of from work to visit the doctor ...

Ja, they do ask, why are you going to the doctor every now and again?[7/3]

Especially if you are not sick, like ...

Ja, because they ask me, are you sick. No I'm just going to the ... but usually when they ask me I say no I have to do the check-up because of the meningitis I had[7/3]. The doctor is still checking for the meningitis.

OK, but it can be very difficult ...

Ja,

OK, so would it be easier if maybe once a week, he was able to see people for instance until 7 in the afternoon or one Saturday morning a month, something like that.

Ja, one weekend a month[7/3]

And then, I don't know if you experienced it, but when he goes away on conference or on holiday, did you ever had a problem that you needed him urgently, say a rash, and you wanted to know what it's about, and you phone and they say no he is on holiday.

No, but then the last time I see him, he was going[7/3].

Just in time. Now that happened to another lady, she had a terrible rash from Viramune, and he wasn't here. How would that make you feel?



I don't know, maybe before I know that lady from the medical aid, I don't know, I never asked her about the medication, I don't know if she does now, but I think it's going to be a problem, but I'll try to go to the other doctor[7/3]. Usually I will have to tell the doctor my status and all those things. But it would be somehow not easy. Prepare the doctor ... Because sometimes, other doctors, when you are like with that doctor for the first time, he just want to know your history, from back then[7/3].

That is a difficult one, because we can't expect him to be here everyday of the year. Hm, but maybe if he had someone working with him ... did you know Esme, who worked here. The nurse.

I think I know ... ja,

If there was someone like her here, whenever he wasn't, someone to cover for him when there is an emergency or something, not like when you have a terrible medical emergency, then you go to the emergency room. I mean like you have a rash and you need to know what to do now. Or you are having diarrhoea, what now. Would you consider asking her what to do, if you know her.

Ja, I think I will because she is also working with the doctor, maybe she knows my files and everything[7/3].

Would you prefer someone who is working with him and knows your file, or someone else who is also specialising in HIV but doesn't know you at all.

I think I prefer someone who is working with him. Someone I know and know what he would say[7/3]

OK, so if you have an medical emergency at the moment, like a rash, you would call that lady from the medical aid. She's only there at office hours. So weekends are still a problem.

Ja,

OK, what would you do then? If it's terrible, if it's not like maybe I can wait until Monday.

Then I'll just go to any doctor. But it's nice to know if maybe some ... if there are some other doctors who ... I don't know if all of them know about the HIV related side effects, or ...

Ja, I think most of them know, if they don't they have this book with all the side effects of all the medication in it. And they can check on it. But what most doctors don't have, they don't see patients with HIV, some of the side effects you just leave it, it will go away, some of it you must treat actively, some of it means you must stop the medication immediately. That is not the knowledge of most doctors who don't specialise in HIV because that you learn when you are working ... it don't stand in the MIMS because the MIMS is only a pharmaceutical type of book, and tell you this is what you can expect. But it doesn't tell you what to do with it. so it's problematic if you can't go to someone whose ... would it help if when he goes away, he let say the HIV patients know, listen I'm going away for this and this time, and if you have a problem, go see this doctor. Then he maybe can brief that doctor about the patients he have and if he needs the files he can get it from reception. Then you know that is also an HIV doctor,

Ja, and then maybe at least he knows more about the patient, ja

At a stage, we had something like a reminder system. Usually you go every 3 or 4 months for blood tests. Then we send and sms or and e-mail or phone you and tell



you it's time for your blood tests. Do you think that's a good system, or do you think people may feel you are intruding on their adulthood. They are big enough to look after themselves.

Like me, I feel you are just reminding me, you are helping me, because maybe I might forget, or something happen and then I totally forget, or other people, even if you are old, you might take it lightly and say no ... I think it helps[7/3]. For me

*Would it be OK for you if we send you and sms. But it will probably be a type of generic sms. We won't say, Hi * go for your HIV tests. Something like it's time for blood tests. Because you will have the paper already.*

Like with my medication, every time they remind me[7/3], OK, they are going to send me my medication on, between this dates, if maybe I'm not going to be available, then I must tell them at which address can they ...

There should be good communication ...the medication is delivered at your work, home?

Sometimes they deliver it at my work, sometimes they deliver it at my place[7/3].

Depending on where you are

Ja, depending,

Is that easier for you than having a script and go to a pharmacy to get the medication?

I think it's much easier when it's delivered[7/3].

Would you be scared if you go to a pharmacy and get this ...?[7/3]

Ja, I think I will, because some other guy, I think he used to give me this medication, and then he started asking why are you taking all this medication?[7/3] You are so young. And I say no, I might be young but I'm sick.

The laboratories. Do you have any problems with them when you go for your blood tests. Do they ask questions or are they funny or ...

No, firstly I was scared maybe they will ask me questions or what. Especially if I'm treated maybe by African black ladies. I thought maybe they will ask me some other questions, what happened or what-what. But they are OK[7/3]

That first time was difficult?

Ja, the first time, even first time going to see the doctor. Now I feel I'm comfortable, and I hope, maybe as time goes on, with my status as well[7/3].

The medical aid, you have a lady you can call, is that only for questions about your health, or if you have a problem with something that's not paid, or the delivery people is funny and say no they can't ... can you call her and find out what is the problem?

Ja, ja, because I was also calling her, they were taking the money from my MSA and then I found out that I don't have the money for anything. And then I phoned her, and then she was checking the system and she found the mistake so she rectified all[7/3] the ...

OK, so she's your contact at the medical aid for anything.



Anything, even for my blood tests also, she remind me, and for my prescription, because I think it is for 6 months, when it's about to finish, then she phone me and tell me that I must get another prescription from the doctor[7/3].

OK, so that helps a lot. She is quite available, you can phone her and she's there. It doesn't happen a lot that you try to get hold of her and she's just not available.

No, no ... because she's sometimes the one that's phoning me, I'm just checking up.

Would you consider using things like a help-line[7/3], if it's now not related to your medical aid?

Ja, I can use it as long as it's for the relevant answers[7/3] or what.

And booklets and things like that, if he were to give you a booklet, say you have questions about specific diet when you have diarrhoea, he have a little pamphlet or booklet about it and he give it to you. Would you take something like that or would it be difficult for you to have literature like that lying around at home with HIV stamped all over it.

No I would read it, I would say, no it's informative[7/3].

Do you have access to the internet?

Internet, yes

Can you access information if we supply you with nice sites to go to.

If it's not specific, because it's like I use it at my work. Why are you ... because they check our internet[7/3].

OK, so you would rather not use that

Ja, I'd rather not[7/3].

So e-mailing you with stuff won't work. So it's more telephone, one to one or booklets then.

But maybe if you send me the information, it's there, just go and read it. I will go and read it. Because it's related to my work[7/3].

What do you believe about alternative medicines like the African potato? Can it help?

For me, those things, I take them as supplements[7/3].

OK, but they are not as strong as the medicine itself?

Ja, ja

So you take it along with your medication?

Ja, but it also depend if they are clashing with your medication[7/3]. Some of them, I'm afraid to take them, because, unless, unless ... but I also take something like vitamins, multivitamin to ...

Ja, it can't do any harm



Ja, maybe if it's something that's been researched in the market, and I know more about it[7/3].

Most of the plant and herbal medicines don't go through the harsh medical research other medicines are submitted to.

There are other people they are taking this Chinese tea, a lady came to work, she was promoting this tea. She said she was dying from HIV and then she start taking this and now she is OK, but I'm afraid of this stuff.



Appendix J: Categorizing of verbatim and recorded responses from participants

<p>“... accept whatever happened, and embrace it, because it’s something that can bring you closer to God ... I actually accepted it and entered the debate where I said, haven’t I been positive, would I be this involved in the church?”</p> <p>“I believe it can be cured from God.”</p>	<p>Religion facilitate hope and acceptance</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Culture and religion</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY</p>
<p>“... because the traditional doctors he can give you a medicine ... that medicine, it can clean all that virus in your blood, and give you the new blood. So it helps ...”</p> <p>“... previously I went for that medicine, but then it didn’t help me ...”</p>	<p>Traditional medicine</p>		
<p>“... because you are female, with this culture thing, always thinks that men know more than females ...”</p> <p>“... they don’t have a say at all ...”</p> <p>“Many black women are very dependable on their men. They will do whatever he say should be done. They would leave their kids, even if it is his kids, to stay with him, if that is what he says. They will have sex without a condom rather than take the risk of him leaving her for another women. I’m not like that, because I know better ...”</p> <p>“... especially those men from rural areas, they still say ... but it also has to do with the culture. You’ll find that he is educated, but he is still making the rules ... even in terms of lifestyle, they way you are living, he can tell you, no, you are a woman, you are suppose to do this, you must bring your salary ... all those things, you know. It has a lot to do with the way they grow up at their home ...”</p> <p>“... she is not woman enough if it’s not natural. She is taking the easy way out if she goes for a caesarean section ...”</p>	<p>The traditional role of women</p>		
<p>“I don’t want flu at all. I panic. I make sure I get my medication ...”</p> <p>“... every time I was sick I would rush, you know, I just didn’t want to ... even if it was a little thing ...”</p> <p>“... because at that stage I was got so frightened, then I thought maybe, because those days it was like you can die tomorrow ...”</p> <p>“... fear, not HIV/AIDS kills. Fear can cause a person not to go onto treatment ...”</p>	<p>Fear</p>		



<p>“... it’s not easy to forget this, unless you don’t want to drink them. In the early days when I was feeling rebellious, I used to forget hem, I wanted to forget them ...”</p>	<p>Rebellion</p>		
<p>“... it’s part of your life ... it needs to be done ...”</p> <p>“You need to come to a point where you know this is who and what I am ... you need some resilience to overcome underlying issues and to face reality.”</p> <p>“... it is important to get over the barrier of medication before you start ...”</p> <p>“I didn’t take my medication the following day ... I was making a conscious decision that I mustn’t start taking this the following day because as I said I hadn’t established a routine ... going away, and it doesn’t help me to establish a routine. So then, the jelly bean thing I think will help ... so you can practice ... enough time to establish a rhythm ... without being too afraid of making a mistake ...”</p>	<p>Acceptance</p>		
<p>“I can’t afford those medications because this treatment is for my whole life ... and the medication is too expensive.”</p> <p>“... if you are not working, you don’t have any income or what, you just listen to the boss, the boss is the husband. Because they are the ones who are making the money. Without them you won’t survive. So they just listen to them ... I think the problem can be when it’s about money ...”</p> <p>“... my husband helps me ...”</p>	<p>Financial dependence</p>		
<p>“I wasn’t prepared but I said, because it’s for my health, I’m ready to make a plan.”</p> <p>“... some of the times they are late to make their payments and then I’m making those payments.”</p> <p>“I’ve told you, I couldn’t get my medication for this month in time ... I had to fight those guys ... you tell me I must go home without medication, give me one tablet ... give me two tablets, one for the evening and one for the morning, then tomorrow I will come. I’ll get money somewhere ... it’s hard to negotiate with these people anyway. You go there they want their money there and then.”</p> <p>“Paying partly for self ... it’s difficult to make co-payments, have to compromise ...”</p>	<p>Strategies to sustain antiretroviral therapy</p>	<p>Cost of antiretroviral therapy</p>	
<p>“... sometimes it takes time to get the ARV’s from the government hospitals ...”</p> <p>“... no money and no medical aid ... it’s the end of the road. They have no option ...”</p>	<p>Consequences of insufficient funding for antiretroviral therapy</p>		



<p>“... when you have the medical aid, you think you are protected. And all of a sudden you have the medical aid, it goes through, but then before they give you the medication, then they tell you the system has changed ...”</p> <p>“... now every month I have to pay, because my budget is now, is now minus 300 ...”</p>		<p>Implementation of the Medicines Amendment Act No 89 of 2004 by the South African Government</p>		
<p>“... usually it happens at night, then I felt, I want to throw up ... I say ah, today I won't take the second tablet. The last ... the evening one. But now, I don't care. Even if I feel, I think I only done it once. That other time I felt everything was here. And the next time I felt like that I said, you know what, I don't care, if I throw up, then it will be, but I'm taking this one ...”</p>	<p>Mind over matter</p>	<p>Managing side-effects</p>		
<p>... “if you take the tablets on an empty stomach, you get a runny tummy ... if you eat something but it's too small, you ... you end up as a runny tummy. So that's how I discovered my portions ...”</p> <p>“... personally I don't like eating in the morning. So I had to learn to eat a particular ...”</p> <p>“I will drink stuff like ... and I'm also weird, because I will dilute it with lemonade. So it's weak, but if I just make that mistake, then I cannot sleep the whole night. I can't sleep at all. So I've just disciplined myself to say I don't do that. I can't do it. If I sleep ... I do (it) get vicious nightmares.”</p>	<p>Lifestyle changes</p>			
<p>“... as I also asked the doctor to change me from it, because sometimes it will make me feel so nausea ... sometimes I couldn't even take my vitamins, because I'm just too nauseas ...”</p>	<p>Request change of treatment regime</p>			
<p>“I'll go to the doctor ... I'll wait for two days, and then ... to see if that thing continuous. And if it continuous, I'll go to the doctor ...”</p> <p>“... if you drink any medication and you then have a prolonged runny stomach problem, it actually comes out of your system, because it doesn't stay in as it is suppose to ... if I had diarrhea, I would phone the doctor, tell him ... then I came through and we spoke about it ...”</p>	<p>Seeking help</p>			
<p>“... when I go to a doctor, I expect him ... also alert me of the side-effects ...”</p> <p>“... but for the first week it was, after taking them in I just feel dizzy, but actually it was not that bad as he told me before: For the first</p>		<p>Information regarding side-effects</p>		

Side-effects of antiretroviral drugs



<p>week maybe you will not be fine with the medication but you must just proceed ...”</p>				
<p>“I mean people say it will make you sick, it will make you feel nauseas, it will make you this, it will make you that. So I needed to be psychologically prepared to fight whatever ...”</p> <p>“... my body is getting used to it ...”</p> <p>“I just wanted to change it again ...”</p> <p>“... they made me scared more than anything else, ja, but I didn't stop because of this ...”</p>		Opinions and emotions regarding side-effects		
<p>“I have a system going. Most of the time I don't even realize that I'm eating something ... I'm so used to my routine ...”</p> <p>... “it's a habit ...”</p> <p>“... normally I take it during my tea break, like half past ten, eleven, because then I know it's my tea break. I just have my tea and then I make sure that I take it ...”</p> <p>“... might be a problem. I think four times is just a bit too frequent. I have to carry a lot more stuff with me ...”</p>		The ability to incorporate treatment in daily routine	Treatment routine	
<p>” ... sometimes I go of at 6 o'clock in the afternoon ... then I'm just going to wait until its 10 o'clock ...”</p> <p>“I have an internal bleeper ... I went out with friends for supper, but at eight o'clock, I just went to the ladies, because by then I had eaten something, and I just drank my medication ... I watch the time quite closely.”</p> <p>“I've changed it in December because I wasn't waking up that early”</p>		Coping with change in a daily routine		
<p>“... it is easier, when you start on treatment, to do it from a comfortable place and circumstances ...”</p>	Perceived importance of a treatment routine	Establishing and maintaining a treatment routine		
<p>“I just sit down and I think about it ... I consciously thought about it because the doctor explained to me ... then I just decide what would be the easiest for me ... it's more or less really understanding what I do like and what I don't like ...”</p>	Pointers to establish a			



<p>“Since the time I started seeing you, I’ve sometimes during the weekends, I was laid backed, I was very negligent, sometimes I would forget to take my medication, lying in bed and say I will take it at whatever time. But since we started meeting, I make sure that I take it on a daily basis. Because maybe, I don’t want a negative report, I don’t know, but then it helps.”</p> <p>“You think your mom being the person who gave you the medication in the beginning ... helped you to establish a pattern.”</p>	<p>The role of a support person</p>			
<p>“... personally I don’t like eating in the morning. So I had to learn to eat a particular portion ... have to force yourself ...”</p> <p>“I always have a fruit bar in my bag ... because people don’t necessarily eat at the time that I need to eat ...”</p> <p>“I must make sure that whenever I’m traveling I must have maybe a bottle of water with me so that ... usually I do have, it’s just that I was in a hurry ...”</p> <p>“You must make it easy for yourself. You for instance, prepare a snack and keep it together with your tablets on your bedside table. Then when you want to sleep in a bit, you wake up, eat and take your tablets, and go back to sleep again. All this entails that a person should be willing and able to plan ahead.”</p>	<p>Strategies to maintain a treatment routine</p>			
<p>“... nowadays I’m on time ...”</p> <p>“... sometimes I feel like I’m OK, why should I take the medication?”</p> <p>“Although, at the end of it all, you need to be grown-up about it and you take control again. It needs to be done, and it will be done ... counseling and special care during this time can be very helpful ...”</p>	<p>Adherence over time</p>			



<p>“... that’s why I also prefer just going to ... I don’t prefer to like jumping all over, because I’m thinking when they look at the file they’ll get the medical history from there ...”</p> <p>“I prefer to go to doctor *, because he knows my status, even whatever he prescribes for me ...”</p> <p>“... she knows my files and everything ... I think I prefer someone who is working with him. Someone I know and know what he would say ...”</p> <p>“And then the doctor was not around and I went to another doctor and the said stop it immediately. Because I also don’t understand these things, but if this leaflet says if there’s a rash, stop, then I say stop it.”</p>	<p>Importance of continuity of care</p>	<p>Accessibility</p>	
<p>“... he was my doctor, but I will go to him with flu ... he’s a good doctor, but I never up to this day ... told him my status. I did never. But he was our family doctor ... I just self couldn’t ... I would just let him treat me, you know and then, forget about whatever happened to me ...”</p> <p>“... it’s like I found (previous HIV specialist) again. But I still didn’t tell him ... I was not honest with him ... it makes it easier ... not doing the blood tests, the HIV test ... if this is how I’m going to come out of this, then I’ll keep it that way ... I sort of like engineered, putting him where I wanted ...”</p>	<p>Reluctance to disclose HIV status to a doctor other than primary HIV care provider</p>		
<p>“I went to just an ordinary GP. It was like I’ve started everything from scratch ... I went to him as if I know nothing. So they took blood. I knew that after the first day that the test would be positive. He’ll take over, only to find he had no knowledge about ... he referred me ...”</p> <p>“I couldn’t go to any other doctor, start all over again.”</p>	<p>Changing from one primary HIV care provider</p>		
<p>“... it’s hectic in the morning ...”</p> <p>“... my doctor he can only see patients after a certain time ...”</p> <p>“I’m a very busy person.”</p> <p>“... my work also, it doesn’t allow me to, every time, go see doctors ... is it available at four. Or after, past four ... I don’t want to take time of at work ...”</p>	<p>Lifestyle and accessibility of primary HIV care provider</p>		<p>HIV care provider</p>



<p>“I’m troubling now ... to get the appointment ... I don’t want him ... to be burdened by me, but surely I need some surety ... it’s full ... suppose I was dying by that time, then what? Why do I have a doctor then? But you still don’t see the doctor ... that means I’m just a statistic ... I didn’t like it.”</p> <p>“I can’t secure an appointment with him because it’s so busy, up to now ...”</p> <p>“But if I can’t find him, they say it is full. I understand there’s lots of other people, there’s thousands of other patients, but, think about it, what if I was dying at that point in time.”</p>	<p>Accessibility of providers</p>			
<p>“... the staff are professional ... obviously they work with our files, so they might know, whatever our status is, or what have you, but I see people smiling, people talking, treating you as a person, as a human being. And I think, that just give you value ...”</p> <p>“... he has a warm personality and sometimes you know, when you got to the doctor, you see, you are kind of tense, and he just talks about small little things, the economy, politics, small little things, just to put you at ease ...”</p> <p>“I’m relaying on his expertise.”</p> <p>“... they are always willing and prepared to help you ...”</p>	<p>Positive relationship with health care provider</p>	<p>Approach of health care providers towards people living with HIV/AIDS</p>		
<p>“Me seeing him was at my own request, because he didn’t want to see me. He just said I can give you numbers of people that you can consult. And I said no-no-no, but I need to understand what are the implications of all this. Can I please see him? And then he said ... you can see me only after two days ... and also being a person that I’ve seen for years ... I’ll never recommend him to anyone”</p> <p>“The government hospitals, you find that the nurses they don’t even treat them well. It’s like they are afraid, or the reception that is only for HIV ... I (will) never (go there), because I’m afraid to go in there”</p>	<p>Negative relationship with health care provider</p>			



<p>“... you and me can both speak English and still not understand each other. We may understand different things from the same language. But I ask if I don’t understand, or I’ll correct you if I think you misunderstood me, just like you do ...”</p> <p>“... you can tell them if they don’t understand they must ask whatever ...”</p> <p>“... new information ... and then you start to treat it as new information, then they would say, I mean, that has been my point all along. But you never said, or it never came out ...”</p>	<p>The influence of language and ethnicity of HIV education and subsequent adherence</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Knowledge regarding HIV and antiretroviral therapy regime</p>	
<p>“I think because of, they lack information, or ... you know our culture, I think the cultures too, they make this thing very much difficult because mostly the black people, they will tell you lies about HIV and AIDS. They say they can cure it, they can do whatever, but there is no such. I don’t believe that. But there’s lot of stories, from them ...”</p> <p>“I think if they can have this information, you won’t get suicides and all this rapes. You know if you rape an innocent baby, you rape a young child, because they got the information that if they are HIV and sleeps with a ... like a virgin, and you gonna be cured. There was no lies. Even if I read books after that, it was exactly what he said ...”</p>	<p>Myths and misconceptions</p>		
<p>“... that pamphlet, cause it is with Combivir they’ve got a paper that they put every month, please take your medication at the same time everyday, so that it could work. So that paper, the pamphlet that I’ve got from them said the same thing ...”</p> <p>“... doctor * he explained a lot to me ...”</p> <p>“I once phoned the help-line, they were not helpful at all ...”</p>	<p>Sources of information</p>		
<p>“I did not read a lot about treatment before ... I was really opened after ...”</p> <p>“I didn’t have a clue except for the general knowledge, I mean, you read and sometimes on TV ...”</p> <p>“... more information as to how you can get resistant towards the drugs ... so I’m not clued up on that ... it’s when you don’t have information that it’s very disappointing ...”</p>	<p>Perception of level of knowledge</p>		



<p>"I want to be on treatment because I want to live ..."</p> <p>"I come to terms, I have it, but I want to live long ... I believe I live long ..."</p> <p>"... let me rather take my medication and my vitamins. I'd rather reduce my vitamins. I'll take two out of the three, and some of them I'll have round about ten. But I made sure that I take my Combivir ..."</p> <p>"... if the lifestyle would demand a change or it's making it difficult for me, I would, ja, I would ask for an alternative ..."</p>	<p>Desire to live</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Trust in antiretroviral therapy</p>	
<p>"I think it doesn't make it to grow. It become more, it lessen the ... because they told me I'm not healed, so I didn't understand what is happening to the virus. Maybe it's there but it's limited ..."</p> <p>"I know it's not a cure, so I must follow whatever he tells me, because it's not a cure. Make sure I don't do the wrong thing ..."</p> <p>"... take treatment and to live happily ... not taking treatment I think is strengthening the virus ..."</p>	<p>The power of the drugs</p>		
<p>"... it's a way of monitoring what happen ... fortunately, my job is monitoring and evaluating, so it's not a foreign concept for me ... it's necessary ... it also keeps me on my toes ..."</p> <p>" ... tell me if the medication is working or not ... the tests will tell you ..."</p>	<p>Monitoring treatment efficacy and detecting toxicity</p>		
<p>"I won't place a lot of value on antiretrovirals, by themselves. Or a lot of value on hm, like a diet, by itself, as a stand alone thing. There has to be perhaps the antiretrovirals, the diet, everything together ..."</p> <p>"I take them as supplements ... it also depend if they are clashing with your medication ... maybe if it's something that's been researched in the market, and I know more about it ..."</p>	<p>Antiretroviral therapy and alternative therapies</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">The influence of stigma</p>	
<p>"... even when he is married he will say it's not me, it's you. He will blame her ... (<i>one lady told me that someone she know who is HIV positive was banned from her own home by her husband</i>) ... Ja, even if he is also positive ..."</p> <p>"HIV is not really a death sentence ... even you who are healthy, you can die even now and I can live longer than you ..."</p> <p>"... the likelihood of that person being chased away and the stigma would fall on her ... it's always assumed that the problem lies with the woman ..."</p>	<p>Myths and misconceptions</p>		



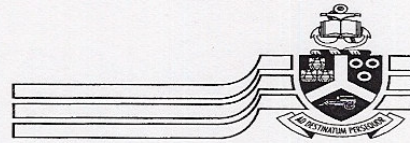
<p>“... also the issue of fear to be judged as an outcast ... something less than human ...”</p> <p>“I don’t want people to start being mean to me because of my, because as much as, people talk about the illness openly, but hey haven’t actually accepted it. So I think what make the situation, what normally makes ... especially people dying very ill, is the fact that they get to be rejected ...”</p> <p>“I put it in unlabeled containers ...”</p> <p>“... maybe if I can tell my friends, then they will start to isolate me ...”</p>	Impact on treatment	Reluctance to disclose HIV status		
<p>“So I’m thinking what will this persons be like if you undergo some difficulty”</p> <p>“... there is a big difference between general support and HIV related support, I think so, I don’t know ...”</p> <p>“I haven’t been sick you know, and that will be the time when you see if people are helping you, supporting you. I was forever like this, not wanting to feel bad, it’s only when I got the results, first time you know, I ten to ... but after that, I was not sick ...”</p>		Perception of available support		
<p>“... you can get whatever pills are out there, but if emotionally you are not OK, if you don’t have a support system, it won’t work ...”</p> <p>“... you need to identify somebody out there ... because if you don’t have a person to talk to, this thing will become worse, it will stress you more. And stress is one thing that you must avoid at all cost ...”</p>		Importance of support		
<p>“... some other guy ... he started asking why are you taking all this medication?”</p> <p>“... they gave me someone to communicate with ... regarding the medication and the medical aid ... make sure that you don’t get your medication a month late ... what if I start to have a problem and I dial the line and she’s no longer there?”</p>	Formal	Sources of treatment support	Support	
<p>“I haven’t been to counseling because I feel that at the moment, this child is more important ...”</p> <p>“... you kind of look out for each other. In a very veiled way ...”</p> <p>“... him remind me was an indication of him being comfortable with this. And think it would have been quite problematic if I had to take this without him knowing. It was then always as if I had to play hide and seek ... and I think that would have interfere with my adherence ...”</p>	Informal			



<p>“... the lady phoning you ...helps to get you through the stages when you feel down and you don't want to drink it ... ja, it helps sometimes because they ask me like other questions, are you using the condom, all those thins, it's like keep you reminded, say you must follow this things, it's so important in you life ... I just feel that they are concerned ... I take them as the people who knows and are helping me in some other ways ...”</p>	Formal	Sources of emotional support		
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Appendix K: Faculty of Health Sciences Research Ethics Committee Approval



University of Pretoria

Faculty of Health Sciences Research Ethics Committee
University of Pretoria

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Soutpansberg Road Private Bag x 385

MRC-Building Pretoria

Level 2, Room 20 0001

Date: 28/09/2004

Number	: S193/2004
Title	: Factors associated with adherence to antiretroviral therapy for the treatment of HIV infected women attending an urban private health care facility
Investigator	: Heila E Aspeling, Dept of Nursing Science, University of Pretoria (SUPERVISOR: PROF N C VAN WYK)
Sponsor	: None
Study Degree	: M. Cur (Clinical)

This Student Protocol has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 28/09/2004 and found to be acceptable.

Prof P Carstens	BLC LLB LLD (Pret) Faculty of Law
Prof S.V. Grey	(female) BSc (Hons); MSc; DSc: Deputy Dean
Prof V.O.L. Karusseit	MBChB; MFGP (SA); M.Med (Chir); FCS (SA): Surgeon
Dr M E Kenoshi	MB,ChB; DTM & H (Wits); C.E.O. of the Pretoria Academic Hospital
Prof M Kruger	(female) MB.ChB.(Pret); Mmed.Paed.(Pret); Ph.D. (Leuven)
Dr N K Likibi	MB.BCh.; Med.Adviser (Gauteng Dept. of Health)
Dr F M Mulaudzi	(female) Department of Nursing
Miss B Mullins	(female) BscHons; Teachers Diploma
Snr Sr J. Phatoli	(female) BCur (Et.AI) Senior Nursing-Sister
Prof H.W. Pretorius	MBChB; M.Med (Psych) MD: Psychiatrist
Reverend PDG Richards	B.Th. (UNISA), M.Sc. (Applied Biology) (Knights), M.Sc (Med) (Wits), TechRMS, DipRM
Dr L Schoeman	(female) Bpharm, BA Hons (Psy), PhD
Dr C F Slabber	BSc (Med) MB BCh, FCP (SA) Acting Head; Dept Medical Oncology
Prof J.R. Snyman	MBChB, M.Pharm.Med: MD: Pharmacologist
Dr R Sommers	(female) MBChB; M.Med (Int); MPhar.Med
Dr TJP Swart	BChD, MSc (Odont), MChD (Oral Path) Senior Specialist; Oral Pathology
Prof C W van Staden	MBChB; Mmed (Psych); MD; FTCL; UPLM; Dept of Psychiatry

Student Ethics Sub-Committee

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Advocate A G Nienaber	(female) BA(Hons) (Wits); LLB; LLM (UP); Dipl Datametrics (UNISA)
Dr S J Cronje	DD (UP) – Old Testament Theology
Dr M M Geyser	(female) BSc; MBChB; BSc HONS (Pharm); Dip PEC; MpraxMed

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MBChB, M.Pharm.Med: MD: Pharmacologist
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Main Ethics Committee - University of Pretoria

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Students Ethics Committee – University of Pretoria